UBC Centre for Human Settlements

HOUSING AND COMMUNITY PLANNING

CHOICE, VOICE and DIGNITY: Housing Issues and Options for Persons with HIV Infection in Canada A National Study

Sharon Manson Willms

Michael V. Hayes

J. David Hulchanski

December 1991

A Report Funded by

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HEALTH & WELFARE CANADA

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CHOICE

"One of the most important issues is to put everything together so that a person maintains the freedom to choose: where, how and with whom to live. This means informing them of their options, providing a range of alternatives, and trying to understand their needs and the needs of the family and friends."

VOICE

"We need to count on existing expertise, both in terms of specialists and those involved in community development, to work in collaboration, to consult those most affected, and to act."

DIGNITY

"AIDS reveals the general dehumanization of care in our society."

-- excerpts from interviews

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Executive Summary

Choice, Voice and Dignity is about providing appropriate housing for persons with HIV. The information in this report was obtained through interviews with persons infected and affected by HIV, with persons involved in housing, and with persons who provide services to those with HIV/AIDS. One hundred and fifty two interviews were conducted in communities across Canada. Five sub-populations were of particular concern: homosexual men, hemophiliacs, women, injection drug users, and sex trade workers.

We have discovered that housing is a major issue among persons infected and affected by HIV. Although important housing initiatives have been undertaken in many communities, there are, in general, severe gaps in housing provision and housing policy. Appropriate housing for persons with HIV in Canada is in short supply. We define adequate housing as housing that is adequate, accessible, affordable, and available.

Housing policies for persons with HIV are urgently needed in Canada. In our opinion, three principles ought to guide the development of such policies: choice, voice and dignity. Persons with HIV/AIDS must be offered a choice of housing options. Options need to be developed in communities across Canada by persons infected with HIV and by local support groups in partnership with local communities and all levels of government. All policies and programs must recognize the fundamental right of humans to live and die with dignity.

Four sets of actors are identified as having a role to play in developing housing opportunities related to HIV: the state, the private market, community-based and non-governmental organizations, and individuals and their families. The role of the state is most important with respect to sources of funds and leadership. Policies must address a continuum of housing opportunities related to the individual's abilities and to the level of care required. Self care options provide the individual the greatest degree of choice in housing Group care options provide slightly less choice, while hospital care options are separate from the housing sector.

There are three groups whose needs are at crisis proportions: injection drug users, particularly young people; mothers with children; and persons who were impoverished before their diagnosis of HIV infection. Also, the majority of persons with HIV have an increased need for support services at the time of transition from one level of care to another such as the move from supported self care to group care. Without housing options, persons with HIV are forced to move into hospital which is the most expensive type of care and an inappropriate form when used to solve a social need for housing rather than a medical need.

The category of persons who are the poorest served by existing services are the injection drug users, particularly young injection drug users. Immediate action is necessary to provide housing for street persons who have tested positive. While in general scarce resources are best used to serve persons who have demonstrated the desire to enter into a recovery program, it is not so in this case. There needs to be housing for the injection drug user to both protect the individual's personal health as well as to reduce the risk of further HIV transmission to the community.

Women with children are underserved and their needs are underfunded. There is little or no recognition of the high cost of meeting the multiple needs of mothers with HIV and meeting the needs of their children. Housing access in this case is limited by additional factors related not only to the mother's needs for prophylactic medical and support services but also by the needs of the children for child care, schooling and support services. These

limitations further restrict the available market for mothers with HIV and almost invariably adversely affects their ability to seek bargains in the market place.

Poor people who learn of their HIV status face many problems when seeking to stabilize their health. Those persons who have been living in housing situations which are characterized as inadequate (unsafe, no tenure, cold, draughts, unhygienic), are faced with an immediate need for appropriate housing and in general have inadequate financial resources to secure it. The situation is even more critical for persons who are homeless at the time of diagnosis. Both impoverished and homeless persons require immediate support to move them into stable and secure housing.

Persons with HIV in transition are in need of substantial forms of support. There is an immediate need to provide stabilizing services for individuals in transition to assist them in moving smoothly from one stage to another.

The stories of individuals with HIV, their parents and families, the concerns of individuals in various service organizations and government officials working in communities all emphasized the lack of integrated responses and the paucity of the choices available to house persons with HIV. While each story is different and each community presents unique challenges and opportunities, some common themes emerged. The principles of choice, voice and dignity mean that the actual solutions to problems must be developed on a local level with the participation and support of the relevant actors and decision makers in the local community. Some of the challenges to solving the problems of housing for persons with HIV are not merely the concern of local communities. The larger jurisdictional issues demand that provincial and federal governments also lend support to local communities in a mutual effort to meet the housing needs of persons with HIV in their home community.

The report contains 25 recommendations on a number of issues including standards of adequacy; integration of services; home care support; additional services required; disability pension; new housing funding; income assistance; reduction of waiting lists; transition houses; and information and referral services.

Appropriate housing for persons with HIV is an urgent problem that demands a coordinated and collaborative response between all levels of government (federal, provincial and municipal) and multiple departments including housing, health, and social services. Partnerships between governments, AIDS service organizations, organizations of Persons Living with HIV/AIDS and the private market sector must be formed to plan and develop responses. The housing problems of persons with HIV cannot be solved by adjusting programs at the margins. There needs to be a multi-pronged approach to the multi-faceted problems that individuals with HIV face in finding appropriate housing.

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1. Introduction

Choice, Voice and Dignity is about providing appropriate housing for persons with HIV. The information in this report was obtained through interviews with persons infected and affected by HIV, with persons involved in housing, and with persons who provide services to those with HIV/AIDS.

It is surprising that housing issues that arise as a consequence of HIV infection have received relatively little attention in the burgeoning literature on AIDS, given the fundamental role housing plays in helping to maintain individual well-being. In addition to meeting basic human needs of shelter and security, housing helps to create individual identity and provides a fixed and familiar location from which the routine activity patterns of daily life are carried out (work, shopping, socializing, and so forth). Housing also provides a base from which to receive services (mail, telephone, electricity, water) and build social networks. All of these activities are vital functions of the human experience, but they take on new dimensions of importance when individual health status is compromised.

Persons with HIV have compromised health status and it is important to their individual well-being to live in an environment that is easy to keep hygienically clean, warm, dry, safe from violence and secure in tenure. These conditions seem important and reasonable for every Canadian and yet we know that these conditions are not being met for the majority of persons with HIV. There are a variety of reasons that persons with HIV do not have housing that is adequate to protect their well-being. The natural course of the illness may render persons with HIV incapacitated and in need of accommodation that is physically appropriate. Many persons face decreased capacity to work or loss of job or income as a consequence of their illness which threatens their security of tenure. Previous shared living arrangements are often no longer acceptable or possible after diagnosis. The loss of a persons' home increases the risk of psycho-social problems and the burden of the illness. Many of the persons with HIV are young and therefore do not have savings or assets in reserve. Location near medical and social services forces many persons with HIV to move into the three largest cities of Toronto, Vancouver or Montreal where prices for accommodation are the highest in Canada.

Affordable housing is becoming increasingly scarce in most of Canada's larger metropolitan areas. Renter households are poorer relative to owner households as real incomes for lower income groups fail to keep pace with inflation. In addition, the stock of good quality affordable rental housing is shrinking in many parts of the country. This is particularly true of Canada's largest cities -- the very places in which the majority of persons with HIV now live.

For persons infected with HIV, fear, ignorance, the nature of HIV transmission, and personal characteristics combine to further complicate their housing situation. Many people face discrimination, loss of income, and stigmatization. The location of health care, social services and social support often creates a need for housing in specific areas of larger cities, effectively limiting the range of choice of accommodation.

Affordability is only one dimension of housing concerns for persons with HIV. Housing must be available in specific locations, accessible to a range of services, and adequate to protect their well-being. These are the salient dimensions of appropriate housing.

At present, few housing policies relate specifically to persons with HIV. Appropriate housing and related social service policies and programs must be developed soon. Three principles ought to guide the development of such policies: choice, voice and dignity. Persons infected and affected by HIV must be offered a choice of housing options. Options need to be developed in communities across Canada by persons infected with HIV and their local support groups in partnership with local communities and all levels of government. All policies and programs must recognize the fundamental right of humans to live and die with dignity.

This report describes what is currently available in policies, programs and options for persons with HIV across Canada. In the following sections the study method is described, what was found in specific housing projects, the housing issues that are facing persons with HIV. A variety of policy options are described that set out the roles for the actors involved in providing appropriate housing for persons with HIV -- the government, the private market, community-based organizations and individuals and their families. The report ends with a list of recommendations that address the most urgent and pressing need for persons with HIV and the communities where they live now and will continue to live in the future.

2. Study Design and Conduct

2.1 Purpose of Study

The purpose of this study was to identify housing issues faced by persons infected with HIV in communities across Canada, create an inventory of existing housing options, programs and policies within these communities, and to suggest policy options to address those issues that are not well covered by existing programs. The study is exploratory with respect to the housing experience of HIV infected individuals, descriptive with respect to current levels of provision, and prescriptive with respect to policy recommendations. This report focuses on the exploratory and prescriptive aspects of the study. The descriptive aspect appears as a separate document entitled *Housing Issues and Options for Persons with HIV Infection in Canada: Summary of Interviews with Agencies and Organizations*, hereafter referred to as the *Summary of Interviews*.

2.2 Method

The primary source of information contained in this report was obtained through interviews with persons living with AIDS (PLWAs), representatives of AIDS support groups, social service providers, municipal housing authorities, and representatives of other community groups across Canada. In all, 152 interviews were conducted in 22 communities throughout Canada between August 1990 and March 1991. Eighteen interviews were conducted with PLWAs, 68 with representatives of community support groups, 31 with health professionals or government representatives, and 35 with non-government representatives of the housing sector. Table 1 provides the distribution of interviews by category and province. Most of the interviews (n=131) were conducted face-to-face.

The sampling method for the interviews was purposive. Forty-four AIDS service and related organizations were contacted by letter in June/July 1990 (Appendix A). The letter identified the objectives of the study and requested a meeting with persons from each organization to discuss

housing provisions and issues pertaining to the organization's catchment. It also asked the support group to identify any other individuals in the area that had an interest in housing-related issues for persons with HIV infection. PLWAs were identified and contacted through the AIDS support groups. Other persons identified by support groups were contacted directly.

TABLE 1
Housing for Persons with HIV: Interviews

	Community-Based Services	Health & Gov't	Housing	Individuals	Totals
B.C.	7	4	8	8	27
Alberta	4	1	1	0	6
Saskatchewan	5	2	0	2	9
Manitoba	3	0	1	6	10
Ontario	25	9	16	0	50
Quebec	13	6	7	1	27
Nova Scotia	3	0	1	0	4
New Brunswick	4	2	0	1	7
Newfoundland	2	1	0	0	3
P.E.I.	2	0	0	0	2
N.W.T.	1	2	0	0	3
Yukon	1	3	0	0	4
TOTALS	68	31	35	18	152

Initially, four target groups were identified as of particular significance to the study: homosexual men, hemophiliacs, injection drug users, and sex trade workers. In the field, women with HIV/AIDS rapidly emerged as another important group to be considered.[1] These five groups are not mutually exclusive. Although there may be housing issues that are unique to specific

1. Our failure to consider women from the outset reflects the fact the HIV/AIDS literature under-represents women's experiences.

groups, many issues apply to all groups. It is not our intention to create stereotypes. The reader is advised to interpret our comments regarding the experiences of each of these groups as being typical of but not specific to all individuals within these categories, unless otherwise stated. Housing issues related to pediatric cases of AIDS were not considered.

2.3 Interview Protocol

Interviews were open-ended but based on an interview schedule devised before field work began. The interview schedules (Appendix B) contained topics of particular interest in the study. All points contained in the schedule were eventually covered in the interviews but interviews were not rigidly structured. Interviewers understood that points of interest (including some not identified in the interview schedule) might arise during the interview and flexibility would be required to pursue these in greater detail. In some instances the interview schedule was shown to the interviewee, in other cases (telephone interviews, for example) it was not.

Flexibility in interview structure should not be mistaken for a lack of rigour in conducting interviews. All six interviewers participating in this study had considerable previous experience in conducting interviews. A sensitivity training workshop was organized for the interviewers to ensure that interviewers were familiar with and sensitive to issues of language, sexuality and compassion that are associated with HIV. The workshop also allowed interviewers to explore their feelings regarding the social meaning of HIV/AIDS and their participation in this project.

PLWAs were assured that their identities would remain confidential. Therefore, no identifying information regarding PLWAs is presented in this report. Most of the PLWAs were interviewed by Sharon Manson Willms, who is a Registered Social Worker in the province of British Columbia and a member of the Canadian Association of Social Workers.

Information obtained from interviews was accepted as delivered. No attempt was made to verify the statements made by interviewees.

2.4 Policy Recommendations

The policy frameworks developed in this report are heuristic devices intended to facilitate understanding of the major housing issues facing persons with HIV/AIDS. The authors accept responsibility for the final result including errors and omissions and gratefully acknowledge the input of all involved in the preparation of this report.

3. Context

To situate the discussion of housing issues for persons with HIV, this section provides a brief overview of the three fundamental areas relating to the issue. These are: (a) the jurisdictional responsibility for service provision in Canada; (b) the epidemiology of HIV/AIDS; and (c) the nature of Canada's housing system.

3.1 Jurisdictional Issues

The Constitution Act of Canada does not recognize economic or housing rights of individuals.[2] Nor does it ensure protection from discrimination on the basis of sexual orientation. By virtue of the Constitution Act, housing, social and health care services are provincial responsibilities. The programs, policies, and distribution of services within each province are, for the most part, idiosyncratic and related to their historical development, although the Canada Health Act does set standard conditions for the provision of health care services.

The role of the federal government has been to stimulate and initiate the development of new services and service forms. It shares the cost of expenditures for housing, health and social services with each province through three venues: the federal/provincial social housing programs, the Established Programs Financing Act, and the Canada Assistance Plan. These mechanisms have been constrained by the federal government to cap budget expenditures and to reduce the domain of what can be cost shared.[3] This has resulted in reduced funds for provincial governments to support existing programs and to meet new and unplanned needs such as those arising out of the HIV/AIDS pandemic.[4] What this means for persons infected with HIV is

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2. *Canada Act 1982*, Government of Canada.

3. Sharon Manson Willms (1990) *Bill C - 69 and the Impact on Medicare: Brief to the Royal Commissions on Health Care and Costs*, Ottawa: Canadian Council on Social Development.

4. J. David Hulchanski (1990) "Canadian Government Housing Expenditures: A Ten Year Review," *Canadian Housing*, Spring, pp. 19-22.

that there is no uniform pattern of service delivery in Canada. Rather, the quality and level of service provision is highly variable. Housing policies to address the needs of persons with HIV have not been developed.

3.2 Epidemiology of HIV/AIDS

Epidemiology is the study of disease occurrence in human populations.[5] Epidemiological information is often used as the basis of health and social service planning and provision. This section briefly describes what is currently known about the epidemiology of HIV/AIDS in Canada, and identifies some of the shortcomings of the epidemiological information as it relates to housing issues.

As of February 4, 1991, Canada's Federal Centre for AIDS had received reports of 4,717 cases since 1979 which met the surveillance case definition for AIDS.[6] About 1 percent of cases (n=57) involved persons under the age of 15 (pediatric cases). The remaining 4,660 cases have occurred among adults. One thousand, eight hundred and eighty three (1,883) adult cases (40 percent) were still alive as of the date of that report.

Among adults, the gender distribution of AIDS cases is markedly uneven. About 95 percent of adult cases are male (n=4,420). The geographic distribution of cases in Canada is also highly uneven, with almost 90 percent occurring in the three most populated provinces of Ontario, Quebec and British Columbia. In absolute terms, Ontario has reported 38.5 percent of cases (n=1,816), Quebec has reported 31.9 percent (n=1,505), and British Columbia 18.4 percent (n=866). Alberta has reported 6.5 percent of cases (n=305). The remaining provinces account for fewer than 5 percent of cases.

From the above it might be appealing to conclude that AIDS is predominately a male disease which occurs in the more highly populated areas of the country. This, however, would be a crude and potentially misleading interpretation of the data, because the Federal Centre for AIDS report includes only cases of AIDS, and does not consider persons who are, at present, infected with HIV but have not yet developed AIDS. It would be erroneous to assume that patterns of HIV infection will necessarily mirror those of AIDS. Thus, when considering housing issues and options for persons with HIV, one should not be lured into assuming that potential problems exist only in localized parts of the country and involve only males. Nor should housing issues be construed

5. G.D. Friedman (1987) *Primer of Epidemiology*, 3rd edition, McGraw-Hill, New York.

6. Federal Centre for AIDS (1991) *Surveillance update: AIDS in Canada*, February 4, Ottawa.

as only relating to persons with AIDS. Housing is an issue for all but a few persons infected by HIV. For many infected people, housing is one of their primary concerns -- either they have no housing, are about to lose their housing, or they require different housing from what they currently possess. Others may be appropriately housed at present but feel considerable anxiety about their future situations, in light of decreasing earning potential and increasing requirements of the physical characteristics of their housing.

It is extremely difficult to derive accurate estimates of the number of persons infected by HIV. Various estimation procedures[7] and models of diffusion[8] or spread of infection have been developed. But, because of multiple sources of uncertainty, modelling techniques provide only rough estimates of the actual number of HIV cases and the actual process of spread. Modes of virus transmission involve activities which are deeply personal and private. Thus, the potential number of opportunities for transmission is not known. Estimating this number is a speculative venture, and any specific estimate is likely to contain wide margins of error. Nor are all modes equally capable of successful transmission, but the variation of successful transmission by different routes of exposure cannot be established precisely.

Confirmation of one's HIV status requires a blood test which, itself, creates a significant barrier to detection. In addition to the nature of the intervention, fear and stigma associated with a positive diagnosis provide further disincentives for individuals to be tested. Persons who are asymptomatic may experience no change in health status to precipitate a blood test, and infected individuals may remain unaware of their infection for years during which time their chances of infecting other persons is undoubtedly great, which introduces yet another dimension of uncertainty to the process of predicting seroprevalence. Further, the impact of public education and awareness concerning the spread of HIV is unknown, but obviously has profound implications for the rate of transmission.

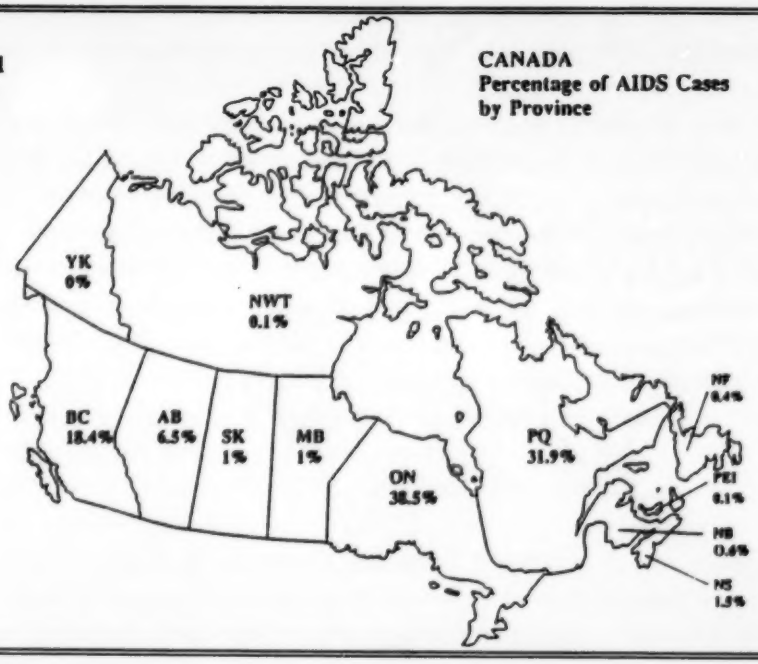
The geographic distribution of infected individuals is not known, but it may be safely assumed to be unequally distributed across the country (see Figure 1). Given the highly mobile nature of contemporary society, it may be a mistake to assume that the current distribution of AIDS cases is a reasonable proxy for HIV infection, especially in light of the fact that many persons with AIDS move to the major centres of Montreal, Toronto and Vancouver after diagnosis to take advantage of the services that are provided in these centres (and not provided to the same level, if at all, in their home communities at present). Geographic distribution of the prevalence data

7. M.H. Gail and R. Brookmeyer (1988) Methods for projecting course of acquired immunodeficiency syndrome epidemic," *Journal of the National Cancer Institute*, 80, pp. 900-911.

8. G.W. Shannon, G.F. Pyle and R.L. Bashshur (1991) *The Geography of AIDS*, Guilford, New York.

FIGURE 1

CANADA
Percentage of AIDS Cases by Province



are skewed by the fact that diagnosis is recorded on the basis of the test result site rather than the actual address of the person tested. The person who goes to Toronto from Kenora for HIV testing, for example, has the location of diagnosis recorded as Toronto.

Our experience with HIV thus far, as an infection which is most prevalent among white male homosexuals, creates diagnostic suspicion biases that place females and visible minorities at a comparative disadvantage for diagnosis. Injection drug users are also at a comparative disadvantage for diagnosis because of the nature of their lifestyles.

In light of these difficulties, one must appreciate that the recent estimate of 29,000 Canadians being infected by HIV as of June 30, 1989, is a crude one at best.[9] Previous estimates have suggested the figure for 1989 is as high as 50,000. Despite the vagaries of estimation, the number of infected individuals is likely to be about an order of magnitude greater than the number of

9. S.A. Marion and M.T. Schechter (1991) *An estimation of the number of persons in Canada infected with Human Immunodeficiency Virus*, Report to the Minister of National Health and Welfare, Ottawa.

AIDS cases. What the number of infected persons will be in future is too fraught with uncertainty to even comment upon. The point is that HIV will not soon go away, and the number of persons affected by the virus will only increase in the next few years. Increasing survival among infected persons as a result of improving effectiveness of interventions will further contribute to the numbers of persons for whom housing will be an issue. In the absence of a cure for AIDS, and assuming the natural history of the disease remains unchanged, we can expect that all HIV infected individuals will eventually develop AIDS. Thus it is imperative that we consider the housing needs of persons with HIV and establish policies and options today.

3.3 Health Status Issues

A. Physical Characteristics

HIV is a communicable disease that is transmitted through bodily fluids -- semen, blood and breast milk. Sexual intercourse and sharing needles with an infected person are the primary forms of transmission. Blood transfusions that took place before 1985 were responsible for infecting 943 people in Canada.[10] The majority are in the hemophiliac group. Deep needle sticks are rare and generally experienced only by health professionals. The probability of contracting HIV from a needle stick is much less probable than, for example, contracting hepatitis.[11]

Without laboratory testing at the asymptomatic stage, knowledge of one's own HIV infection or identifying the presence of the virus in others is very uncommon. Individuals who carry HIV may remain asymptomatic for several years before displaying any of the signs of AIDS, and may only learn of their diagnosis when symptoms typical of AIDS appear. This seems particularly true for women as the typical symptoms have been developed in a male population and do not include gynecological symptoms among the typical lists.[12] High risk behaviours for contracting HIV include intravenous drug use, blood transfusion prior to 1985, practising homosexual or bisexual behaviour, multiple sexual partners and/or having sexual intercourse with a person who

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10. Personal communication. Canadian Hemophilia Society, February 8, 1991. Figures quoted are accurate to January 14, 1991.

11. See discussion in Edward Brandt (1987) "AIDS Social, Scientific and Health Policy Perspectives," *Current Topics in AIDS Volume I*, M. Gottlieb et al eds., Chichester, England: John Wiley & Sons, pp.20-21. Also W. Pfaffl (1988) "Medical Bases," *AIDS and AIDS Risk Patient Care*, H. Jager ed., Chichester, England: Ellis Horwood Ltd., p.31.

12. See for example, M. Froschl, and O. Braun-Falco (1988) "Women and AIDS," *AIDS and AIDS Risk Patient Care*, H. Jager ed., Chichester, England: Ellis Horwood Ltd., pp.152-161.

is infected with HIV. Diagnosis of HIV requires a blood test. Diagnosis of AIDS is made by a medical diagnosis based upon typical symptoms.

Typical physical symptoms of HIV include lymph node swelling of unknown origin, involuntary weight loss, unexplained fever over 38 celsius, chronic diarrhoea, weakness, fatigue, deteriorated ability to work, and night sweats. These symptoms can continue for several years before progressing to AIDS which is defined by the presence of AIDS specific diseases such as pneumocystis carinii pneumonia (PCP), cryptococcal meningitis, toxoplasmosis or various abnormal immunological laboratory test results.[13] There are many opportunistic infections which characterize the early stages of AIDS including thrush, shingles, severe athletes foot, and oral leucoplakia. As the helper cell count in the blood diminishes, there is a concurrent rise in the risk of life threatening opportunistic infections. The average time from initial HIV infection to death has been about 10 years.

B. Psycho-Social Issues

The diagnosis of a terminal illness can trigger psycho-social problems in any person. There are, however, several complicating factors specific to HIV. The three main points where persons with HIV are at risk for developing psycho-social problems are at the time of: (1) diagnosis of seropositivity; (2) the transition from asymptomatic to symptomatic; and (3) diagnosis of AIDS.

As Figure 2 indicates, the diagnosis of HIV in any of its forms may precipitate depression, suicide ideation, suicide attempts and suicide, and/or exacerbate any pre-existing mental illnesses.[14] The long incubation period and inability to predict when the infection will progress can leave the individual in a constant state of stress and uncertainty. Physical decline and loss of attractiveness negatively affects self-esteem which, in turn, negatively affects health status. The fear of possibly infecting others may result in self-imposed isolation and feelings of guilt. Fear of reaction from lovers, friends, family, community and the workplace may result in an inability to seek appropriate forms of support. The experience of discrimination for many persons with HIV is not unusual if they have already identified with the gay community or are injection drug users.

Discrimination escalates with a diagnosis of AIDS. Previously supportive networks may disappear. In cases where homosexual behaviour has been closeted, the fear of being "found out"

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13. John Mills, and Henry Masur (1990) "AIDS-Related Infections," *Scientific American*, August, pp.50-57.

14. See Christian Paquin (1990) "The Importance of Psychological Support at the Time of HIV Testing," *Intervention*, No.86, September, pp.32-38.

may create grave stress and anguish. Internalized homophobia, found to be common in gay men who are diagnosed as HIV positive and subsequently seek support, is seen as a response to long-term negative social conditioning about homosexuality.[15]

About half of all HIV diagnosed persons in Canada are 30 to 39 years of age and about one quarter are 40 to 49 years of age. The combination of homosexuality and a diagnosis of a terminal illness in the prime of life makes it difficult for some individuals to resist the notion that it is a punishment rather than a disease that affects some people who have engaged in high risk behaviour. The new taboo is coming out of the closet as HIV positive, especially with other gay men.[16] Further, given that the vast majority of cases in Canada and the United States have affected gay men (85 percent in Canada), most gay men have friends who have died of AIDS. This personal experience arms the newly diagnosed individual with the knowledge of the intractability of the end, and an understanding of the losses that are yet to come.[17]

For women the psycho-social issues related to HIV are often associated with their status as caregivers in the family. Many women learn of their seropositive status at the time of pregnancy and are faced with the dual prospect of diminished capacity to care for themselves at the same time as the increased demands associated with the birth of a child. Women interviewed in this study expressed a severe sense of isolation, had fewer support networks than men, and admitted to disclosing their HIV status to fewer people than men who carry HIV typically do.

Hemophiliacs confront similar problems as other seropositive men. Given that hemophilia is genetic, many families experience HIV first through the extended family or hemophiliac community. Homophobia is an explicit issue for many men infected through blood transfusion. They are concerned that they will be identified as homosexuals because of their seropositive status. There is a strong association in the minds of most Canadians of HIV and homosexuality, and as discussed earlier there is evidence to support this association. In most communities outside of the three major cities in Canada, there is an avoidance by the hemophiliac community of the use of the word AIDS as a descriptor for an individual's condition.

For injection drug users the diagnosis of HIV can serve as a catalytic turning point and a decision to stop drug use. Diagnosis of HIV may offer an opportunity to intervene and begin a

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15. Gail Henderson Baumgartner (1985) *AIDS: Psychosocial Factors in the Acquired Immune Deficiency Syndrome*, Springfield: Charles C. Thomas Publisher.

16. William Hayes (1991) "To be young and gay and living in the '90s," *Utne Reader*, March/April, pp. 94-100.

17. Federal Centre for AIDS (1991).

detoxification program. According to subjects in this study, this is not always the outcome of diagnosis, and if a change in illegal drug use does not take place then the progression from HIV to AIDS to death is accelerated.

The experience of HIV mixes both sex and death on the landscape of the psyche. These two primal forces in human existence are frightening to contemplate, thus a number of taboos to regulate public discussion have been created. The taboos, while serving the needs of individuals in the community to deal with fear of birth and of death, operate to restrict open discussion and hence acceptance of persons infected with HIV. Fear becomes the operant response of both individuals and the community to the individual. The attendant consequences of actions/reactions based on fear are experienced by the individual in terms of psycho-social problems and then reinforced by the community response to the problems presented.

FIGURE 2

The Psycho-Social Issues Associated with HIV Infection

Uncertainty of Disease Progression

Loss of Some Physical Capacity

Loss of Some Sexual Capacity

Loss of Self-Esteem

Feelings of Guilt

Fear of Reaction from Community

Discrimination and Objectification

Self-imposed Isolation

Overwhelming Sense of Loss

Fear

Depression

Despair

Suicide

Fear for the future is a natural response, and stress coupled with uncertainty may further reduce the immunity of the individual. These factors may impinge on the individual's ability to cope with the disease and limit the support available within the community for similar reasons. It impinges on the ability of the individual to seek and access appropriate resources.

3.4 Canada's Housing System

Canada's 10 million households, on average, are well housed compared to most countries. Sixty percent (60 percent) own their own homes and half these owners have no mortgage. More than half of Canada's housing stock (56 percent) is in the form of single detached houses with another 9 percent in single attached (duplex) houses. Many Canadians, therefore, live at relatively low densities, even though 75 percent of the population is urban.[18]

With the adoption of the Dominion Housing Act in 1935 the Canadian government initiated a permanent role for itself in Canada's housing sector.[19] There have been numerous programs for home-ownership and for the private rental sector ever since.[20] Yet any analysis of housing conditions finds that the housing situation for at least some Canadians is not getting better, and for others, the homeless, inner city poor, and native Canadians, for example, conditions are much worse. Federal housing policies since the mid-1980s have worsened the housing situation of lower-income and special needs groups in Canada by continually reducing the number of new subsidized housing units built each year.[21]

Why are there still serious housing problems after more than 55 years of government housing programs? Virtually all the more serious elements of Canada's housing problem relate to the fact that Canada has an *incomplete* housing system. As the housing system evolved in the post-war years, no provision was made for ensuring that there would be adequate rental housing supply. It was assumed that the private sector would produce an adequate supply of units to match demand and it was further assumed that lower-income households would obtain their housing by the downward filtering of units. To some degree this was true in the 1950s and 1960s. Filtering down of older units in the inner city supplied very poor quality but affordable housing to the poor. In the 1970s gentrification -- the upward filtering of inner city housing from the poor to higher income households -- has resulted in the loss of affordable housing stock.[22]

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18. J.David Hulchanski (1990) "Canada," Chapter 9 in *International Handbook of Housing Policies and Practices*, W.van Vliet, ed., N.Y.: Greenwood Press, pp. 289-326.

19. J.David Hulchanski (1986) "The Dominion Housing Act: Setting the Stage for a Permanent Federal Presence in Canada's Housing Sector," *Urban History Review*, June.

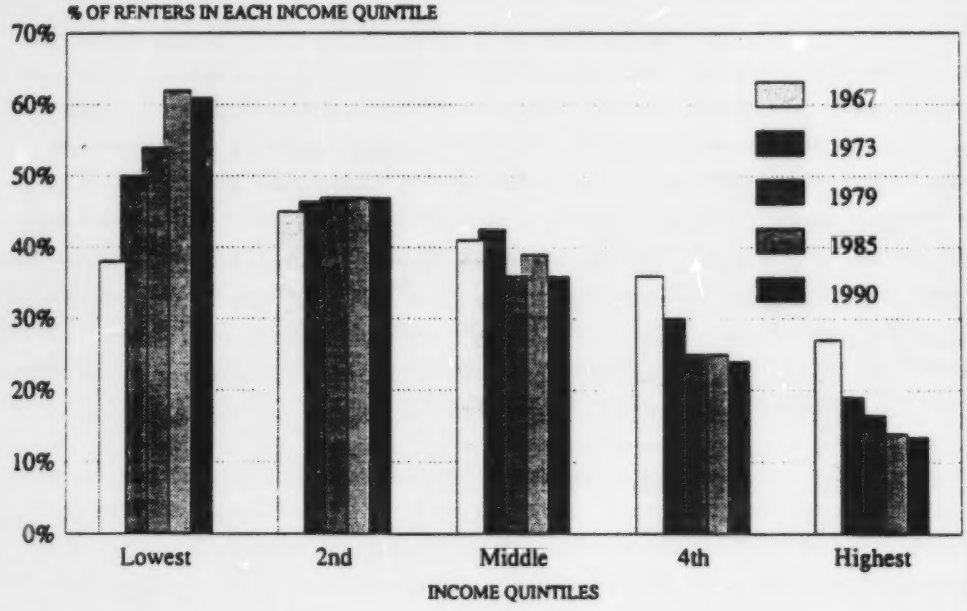
20. Albert Rose (1980) *Canadian Housing Policies, 1935-1980*, Toronto: Butterworths.

21. J. David Hulchanski (1990) "Canadian Government Housing Expenditures: A Ten Year Review," *Canadian Housing*, Spring, pp. 19-22.

22. David Ley (1991) "Gentrification," Chapter 13 in *The Canadian City*, K. Gerecke, ed., Montreal: Black Rose Books, pp. 181-196.

FIGURE 3

Renter Households in Canada
Trends by Income Quintile, 1967 to 1990



Source: Statistics Canada

J.D. Hulchanski, Social Work, UofT

It is when we look at renter households and the rental market in Canada that we find serious problems. Though 40 percent of households are renters, they are concentrated in cities, especially the largest cities. Over 60 percent of the households in the cities of Montreal, Toronto and Vancouver are renters and many are very poor. According to the most recent estimates, 37 percent of all renter households in Canada live in poverty. This is 1.3 million households out of Canada's 3.5 million renter households.[23]

Canada does not have a *complete* housing system. The home-ownership sector works -- all one needs is lots of money and a secure job -- the rental sector does not. The housing challenge of the 1990s is developing a rental housing supply, allocation and maintenance system which works.

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23. Canada, National Council of Welfare (1988) *Poverty Profile 1988*, Ottawa: The Council.

It is a major challenge for two key reasons. First, only 5 percent of the housing stock is non-market housing, *i.e.*, various forms of subsidized public and non-profit housing. Most of these units are of relatively good quality but the waiting lists are very long. The second reason the rental sector is in serious trouble is due to the polarization of the population by income and tenure. As Figure 3 indicates, in just over 20 years, there has been a dramatic shift in the composition of the renter population. Relatively few renters are now drawn from the top two income quintiles. Soon virtually all renters will be drawn from the bottom range of the income scale.

The problem with the private rental sector is that this demand for rental housing is not effective market demand. The people who need adequate, affordable rental housing appropriate to their needs do not have the money to pay for it. These households generate social *need*, not *market demand*. The market responds to market demand, not social need. Yet Canada relies on the private market for the supply and maintenance of most of its rental housing stock. Renters, unlike home-owners, cannot obtain housing appropriate to their needs at a price they can afford. Demand in the home-ownership sector is being met; demand in the rental sector is not. Even worse, good quality affordable rental stock is continually being lost to demolition and condominium conversion. The private rental sector cannot meet renter's housing needs, yet Canada has an extremely small stock of non-market housing.

Persons with HIV who have little or no income must cope with their medical problem and with Canada's incomplete housing system. If they do not already have a secure place in the housing system before their HIV infection develops into AIDS, they will certainly face a severe problem finding appropriate housing -- housing which is adequate, accessible, affordable and available.

4. Housing Issues for Persons with HIV Infection

4.1 The Need for Appropriate Housing

Housing plays an integral role in both health protection and health promotion. For persons with HIV infection both health protection and promotion strategies are needed in order to prevent further transmission of the disease. Prevention is associated with being able to provide security, and security is related to being housed where one can have a permanent address. Housing is the anchor from which one locates oneself in the community, receives and accesses services, and exercises basic citizenship rights. Health promotion approaches view health as a resource for control over one's life, and meeting basic needs, such as appropriate housing, is essential to effective health promotion. Preventing rapid transition from seropositivity to AIDS is dependent upon adopting healthy lifestyle choices that are designed to promote wellness, reduce stress, and increase supportive contacts within the community.

A report by the Resource Information Service of the London Special Needs Housing Group describes the requirements of housing for persons with HIV infection:

> *Their housing should be warm, easy to move around in and keep clean. It should offer privacy and control over their own lives. The effect of stress on their health means that their accommodation should be as stress free as possible. It should offer protection from harassment and physical attack, security of tenure and be manageable financially. Good housing is also housing which is responsive to what people want, which offers them some choice about the way they wish to live and is flexible to changing circumstances. Housing for people with HIV needs to take into consideration the support and care they are likely to require if their condition worsens.*[24]

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24. London Special Needs Housing Group (1987) *AIDS: The Issues for Housing*, London: Resource Information Group, pp. 13-14.

In our view, the need to satisfy these criteria (and others discussed below) indicates that, above all else, housing for persons with HIV must be appropriate. By our definition, appropriate housing is housing which is adequate, accessible, affordable and available. Issues associated with each of these aspects of appropriate housing are outlined below, and summarized in Table 1.

A. Adequate Housing

Housing must be physically adequate. Housing for persons with HIV infection must be warm, dry, mold free, easy to keep hygienically clean and offer a safe, quiet and secure environment. While most Canadians take this list for granted, adequate housing is of paramount importance to persons who are immuno-compromised. The presence of innocuous bacteria normally associated with food and sanitation facilities may prove deadly to a person who is HIV infected.

Canada has, on average, very high quality housing stock. Unfortunately, the poorer quality stock tends to be concentrated in the private rental sector in the larger cities -- just those markets in which housing needs for persons with HIV/AIDS are currently the greatest. The ability of persons with HIV to obtain adequate housing is often constrained by the cost of housing in these markets.

In terms of the state's role in providing adequate housing, the issue may be framed as one of social justice, in that the fundamental right to housing recognized by the United Nations is not being met. Canada has taken no formal action to recognize or implement a right to housing. The Constitution Act, while providing for equal treatment before the law, does not enshrine economic or housing rights, and excludes protection from discrimination on the basis of sexual orientation.

B. Accessible Housing

Housing must not only be physically adequate, it must also be physically accessible. The entrance to the dwelling must be accessible for a person who is weak and in a state of chronic fatigue. A level entry or few stairs to climb are important to a person's ability to stay in his/her own home. A third floor walk-up cannot be considered accessible to a person carrying the day's groceries when they are already fatigued.

TABLE 1

Housing Issues Relating to HIV in Canada

Housing Stock Principles	*Issues for the* Individual	*Issues for the* Community	*Issues for the* State
ADEQUATE	• warm • easy to clean • dry • safe • secure	• protection from HIV transmission	• social justice • social rights • health protection • health promotion
ACCESSIBLE	• level entry • supported bath • space for caregiver • proximity to services	• proximity to support systems • critical mass of concerned individuals	• specialized services vs ghettoized services • rural vs urban
AFFORDABLE	• poverty level incomes except hemophiliacs • income needs vary over course of disease	• local tax rates • hospital bed pressure • less costly for home care	• liability in blood products • tax transfers • minimal market control over housing
AVAILABLE	• rental housing • low vacancy rates • high demand in inner city	• range of housing and support services needed • NIMBY	• multiple centres of services: health, social and housing

Inside the home, there must be room enough to allow a person who is physically handicapped to move about, and to move easily from bath, to bedroom, to eating area without significant impediments. The bathroom should have supports for access to the toilet and the bathtub.

Space for a caregiver to spend the night and/or move around the living area is important to being able to maintain the person at home during bouts of fatigue or opportunistic infections that do not require hospitalization, but require increased amounts of care. Many interviewees noted that a quiet location is an important factor in maintaining their health. Privacy is also important for both psychological and physical health reasons.

The problem of having physically accessible housing for persons who are HIV positive is further complicated by locational requirements. Housing must be reasonably close to shops and public transportation, and to medical and social services. Proximity to services has been a factor in demand for housing located near major hospitals. In Vancouver, the location of St. Paul's Hospital in the city's West End coincides with a greater density of gay men than other areas of the city. This clustering of the gay community preceded the discovery of HIV infection. In Toronto and Montreal, there is a similar finding. Toronto's Casey House hostel and the group home called 127 Isabella are located in the College and Church Street area which is the centre of the gay community, and is also a centre for hospital services. In Montreal, Le Village is recognized as a gay area and Le Plateau as the anglophone gay area. Both are located in downtown Montreal.

Persons living close to the major HIV service centres located in Vancouver, Toronto and Montreal enjoy the advantage of access to more than the centres themselves. The cities contain critical masses of people concerned about, and mobilized around, the issue of HIV. Consequently, community organizations that respond to the needs of persons with HIV are highly developed in these cities, and support is often available from such organizations. In many cases service delivery is more efficient because of the shorter distances involved for both caregivers and persons seeking care. Access to information and to the latest technologies tends also to be greatest in these cities.

While there are obvious advantages to be gained by concentrating resources and expertise in service centres in the largest cities, the consequence of this pattern of resource deployment is that persons who do not live in these cities are underserved. For example, persons living in Victoria must go to Vancouver to have a blood test for HIV. In Regina, there is only one health care professional responsible for the entire HIV population.

C. Affordable Housing

"Most Canadians who are disabled are poor."[25] In studies of the homeless, a strong correlation has been observed between the onset of a disabling condition and the subsequent transition to homelessness.[26] The facts related to income distribution support this observation in the context of persons with HIV. Single adult earners are in a poor position compared to dual earner families and are at a higher risk for sinking below the poverty line than almost all other groups with the exception of single parent women.[27] Many women with HIV infection have children and are thus at a very high risk of being in poverty.

Among the HIV infected population in Canada, hemophiliacs who have benefitted from the federal government's Catastrophic Relief Program are an exception. This program pays $120,000 cash over four years to persons who contracted HIV as a consequence of blood transfusion prior to 1985. Approximately 943 persons have applied for benefits under the Catastrophic Relief Program, the majority of whom are hemophiliacs.

Others with HIV face an accelerated decline into poverty as they are forced to leave their jobs due to illness. Persons able to maintain involvement in the labour force may be afraid to change jobs for fear of being discovered as seropositive as a consequence of medical tests required for life insurance, or they may fear that the added stress of taking on a new job will imperil their health.

The income needs for persons who are disabled are generally more than those experienced by persons in good health. The extra expenses associated with illness and the services required for daily living can be substantial, and these needs vary over the course of the disease. Many people experience severe illness, recuperate and are again able to participate in daily living activities, including paid work. Their income needs are characterized at the early stages as requiring short-term income substitution.

Given that most persons with HIV infection are under 40 years old, and a significant number are under 30, many have not built up significant savings. Also, as the most frequently reported risk for persons with HIV in Canada is through homosexual contact, the majority are not in a

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25. Sherri Torjman (1988) *Income Insecurity: the Disability Income System in Canada.* Toronto: G.Allan Roeher Institute.

26. P. Rossi and J. Wright (1987) "The Determinants of Homelessness," *Health Affairs*, Spring, pp. 19-32.

27. D.P. Ross and R. Shillington (1989) *The Canadian Fact Book on Poverty 1989*, Ottawa: Canadian Council on Social Development.

relationship that resembles marriage as an economic union. Single men in their mid-thirties who are identified as homosexuals are prone to be stigmatized as they do not fit within the cultural norm of "deserving poor" despite the fact that they are indeed sick and in need of financial support. Therefore, the experience of many interviewees is one of having to persistently fight for any or all entitlements provided by the state. Income assistance is stigmatizing for most recipients, but being single, male, mid-thirties and gay is a combination that is destined to ascribe marginality in our culture.

The situation for women with HIV, especially those with children, is very difficult financially. While they may receive income assistance it is usually insufficient to meet both shelter and support needs. Mothers on income assistance who are also HIV positive may be unable physically to access free services such as food banks to supplement their inadequate incomes.

Injection drug users when faced with spending money on housing or drugs to support their habit will satisfy short-term needs. Housing affordability as an issue for injection drug users is experienced more at the level of the community of interest, who are trying to provide appropriate housing at a price that is within reach of the agencies concerned.

Whoever the constituency, there is an obvious gap between income substitutes and the poverty line, whether the money comes from disability pensions or income assistance. The lack of adequate core income programs condemns most disabled persons to live in abject poverty.

Both the community of interest and the geographic community have a concern with providing affordable housing for persons with HIV. The community of interest may be those persons who are active advocates on behalf of persons with HIV and include seropositive members. The geographic community, who are the majority, are the neighbours in the community where persons with HIV live. There may be pressure from rate payers, particularly those in Toronto, Montreal and Vancouver, not to raise taxes to pay for services for persons with HIV. Similarly, the geographic community does not want to have its local hospital beds filled with persons who are there because there are inadequate housing options.

D. Available Housing

Housing availability is closely related to the other three aspects of housing issues. Appropriate, accessible and affordable housing must be available in locations where it is needed. Canada's housing system has no problem producing the higher cost ownership and rental housing options. The problem is making available enough adequate, accessible and affordable housing where it is required.

TABLE 2

Rental Housing Vacancy Rates in the Larger Metropolitan Areas Canada, 1987 - 1989

	1987	1988	1989
Toronto	0.1%	0.2%	0.3%
Montreal	3.6%	4.0%	4.9%
Vancouver	1.1%	0.4%	0.4%
Average for 25 largest Metropolitan Areas	2.5%	2.6%	2.8%

Source: Canada Mortgage and Housing Corporation (1990) *Canadian Housing Statistics 1989*, Ottawa: CMHC, Table 29. Vacancy rates based on CMHC bi-annual surveys of private sector rental apartment buildings with six or more units.

Many HIV positive individuals want or need to live close to the health and social service centres, which puts them into higher priced neighbourhoods than they might otherwise choose. The largest medical service centres in Toronto, Montreal and Vancouver are located in the urban core, which means that persons with HIV are competing in rental markets characterized by persistently low vacancy rates. This severely limits the range of housing options available. Table 2 provides a summary of the vacancy rates for the larger metropolitan areas for a recent three year period. In Toronto and Vancouver vacancy rates have continually been at or below 1 percent. Montreal vacancy rates generally have been higher, however the income assistance rates in Quebec are among the lowest in Canada.

With the exception of persons with hemophilia, the majority of persons we interviewed with HIV were not home-owners. Home-owners who lose their source of income must struggle to maintain themselves in their own homes, while renters must seek appropriate accommodation in the private rental sector which has few available options. The National Council of Welfare estimates that approximately 37 percent of renters live below the poverty line compared to less than 10 percent of home-owners.[28] Factors which constrain the availability of rental accommodation for

28. National Council on Welfare (1988) *Poverty Profiles*, Ottawa: National Council on Welfare.

persons with HIV include: competition on the open market where vacancy rates do not rise above 3 percent; the need for accessible housing as previously defined; and the lack of affordable units in the desirable downtown locations in each of the three largest cities. The aggregate vacancy rates do not take into account the actual vacancy rates in the rental units in the bottom one-third of the price range, the part of the rental market which is under considerably greater pressure than the overall rental market. This observation is underscored by the recent report on distribution of incomes by Statistics Canada which states that "among renters, rent ate up at least 30 percent of income for more than one-quarter of families while for the lowest-income families almost 55 percent of income went on rent."[29]

The availability of financial support for other than independent living is constrained by lack of resources appropriate to the needs of persons with HIV. There are across Canada limited resources for home care support, group care residences, and congregate care facilities. Hospital beds across the country are under pressure, and the lack of available resources for persons being discharged from hospital means that persons with AIDS may be in hospital longer than is desirable. Palliative care beds in the hospital are used for persons with AIDS in the final stage. It has been noted by several health care professionals, however, that due to the lack of available housing in the community, it appears that persons with AIDS have longer stays in palliative care units than other patients. Hospices are another choice, and appear to be appropriate for some persons. The issue for the majority of hospices is the lack of adequate core funding to accomplish the task of supporting people to the end of their lives.

The community has an interest in ensuring that there are various housing services available to meet the needs of persons with HIV infection over the course of their disease. If there are inadequate services to support individuals who are in the chronic stages of the disease, then the alternative is to utilize acute care services which are generally more costly. For the community of interest, the family or supportive network involved with individuals with HIV, there is a burden of care associated with a lack of service. If the only choices are living at home or hospital care, then the supportive family or friends may be unable to provide the level of support required to meet the physical and emotional demands of a person who has HIV on an ongoing basis without respite care and/or other support services. The geographic community may counter any proposals with NIMBY attitudes (not in my backyard) which have created dilemmas for many residential services, whether they are AIDS-related or not. Communication with the neighbourhood and involvement of key persons of influence in the community are essential steps in getting the community to accept housing initiatives.

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29. Statistics Canada (1990) *Household Facilities by Income and Other Characteristics*, Ottawa: Supply and Services Canada, Catalogue 13-218.

As discussed above, the state has played a limited role in making housing available. It is unrealistic to expect the private market to make housing available for persons with HIV in the absence of any financial incentives to do so.

4.2 Issues Related to Housing

While the "four A's" provide a summary of the general nature of the housing problem and indicate standards for appropriate housing, the interviews provided more detailed insight into particular aspects of housing and related issues across Canada. Problems in the delivery and access to services required to support persons with HIV exacerbate existing housing problems or create new ones. Listed below are examples of concerns raised in interviews.

- ***Access to information and education.*** Among the consumers of the services, the health care professionals providing them, and throughout the community in general there are problems relating to those who are not informed, those badly informed and those who think they are well informed, particularly when this involves insensitive service providers. In order to provide adequate service delivery better information dissemination, better training, and better means of communication are needed. For example, depending on the hospital, many of the doctors seem to be unaware of the extenuating social problems of a person with AIDS. Hospitals often are unable to give social services or, in some cases, even medical services. Fear of the disease by badly informed health care providers results in excessive procedures and as a consequence persons with HIV are made to feel like pariahs. Social service workers are often unaware of the serious physical problems experienced by persons with HIV, and expect clients to be able to manage their fatigue or tolerate long waits for services. Staff turnover and holidays interrupt the continuity of services. Many interviewees complained that it took a tremendous amount of energy to educate the service providers and that this investment of their time should be rewarded by tenure of the service provider.

- ***Consultation and participation in decision making.*** Housing should be developed in consultation with the people who need the housing in order to determine individual needs and preferences. There is a danger of forming preconceived ideas about needs and repeating the same errors as in housing other special needs groups. Individuals that are competent to choose should be able to exercise their choice for housing that suits their needs.

- ***Financial security.*** HIV affects most people's economic status and poverty becomes a problem for most. The price of being disabled is high in Canada where in many provinces basic drugs and support services are not provided to those who do not pay. Therapy, drugs, massage, extra nutritious food, and so forth, are expenses that many persons with HIV must pay themselves or do without. The general impoverishment of persons with HIV aggravates the loss of physical autonomy as people are not able to afford substitute services such as taxis when they are no longer able to drive to the grocery store, or to attend to the clinic for medical care. Many HIV infected persons have no immediate family, and become isolated, confused and increasingly depressed by their social situation. Even when there is family or caring friends, many are unable to take care of persons with AIDS because of lack of resources, space, expertise or equipment. Financial independence would alleviate much of the stress currently borne out of the uncertainty and loss of choice caused by poverty.

- ***Access to support services.*** AIDS support groups are for most infected people the gatekeepers to service and information about resources. AIDS service organizations face constant financial insecurity and lack of funds. This translates into a lack of training and communication with various government agencies and the client group itself. There is often a lack of collaboration with other groups and potential partners in the health and social service sectors. Collaboration requires effort and effort requires energy and resources which are in critical short supply in the overburdened organizations. For volunteer-based organizations, keeping the volunteers organized and motivated, under conditions where they are often overworked, is a serious problem. Many groups face a lack of credibility and legitimacy in the eyes of officials and community leaders. There is the problem of getting different populations (homosexuals, women, hemophiliacs, ethnic minorities, drug users) to share the same resources. There is a great need to foster the sense of partnership currently shared by some community groups, and to develop links with groups currently working in isolation. There is also the problem of generally lower than average wages for people who work in HIV-related housing options.

- ***Home care support services.*** There is general agreement that institutionalized forms of housing ought to be kept to a minimum, but there is also an inability throughout the country to meet the needs associated with maintaining people in their own homes. Provision of improved home care services ought to be a priority. There are numerous problems with the quality and quantity of the home care system in each locality for all those in need. Staff training, flexible policies for service, and need for varied types of

services are a few of the most frequently mentioned issues. HIV-related needs appear to only point out the weaknesses in the present system.

- ***Waiting lists.*** There tend to be long waiting lists for the few existing housing options. The people who need housing usually need it quickly. A waiting list of two years for entry into supported housing, a co-op, or subsidized housing is unacceptable for persons with HIV whose health status is related to the adequacy of their housing situation.

- ***Institutional housing.*** It is difficult to put persons with AIDS into existing non-specific institutions; they are often not welcome, and workers often refuse to provide services because they are not well informed. Even in cases where staff have received training for universal protection, issues arise related to homophobia. There are financial considerations, as well as organizational, technical and flexibility problems. Many of the persons with AIDS are young and have come for help only after they are very ill. They are often the type who have lived a very independent lifestyle and then find themselves in a state of generalized deterioration and social rejection requiring significant levels of support. The very nature of an institution is antithetical to the preferences of most persons accustomed to independent lifestyles.

- ***Palliative care.*** The lack of options for non-institutional palliative care is a problem, especially ones which have a minimum of equipment, decent accommodation conditions, and some degree of beauty in the surroundings. The size of rooms has been a problem when people are in a terminal phase and need more than one person to care for them.

- ***Organization of government services.*** Persons with HIV require health care, social services and housing support -- services which are not provided under any one integrated Ministry in any province. The issue is further complicated by the nature of the distribution of jurisdiction -- thus responsibility -- for each of these issues, involving as they do, federal, provincial and municipal interests. Partly as a consequence of organization, and partly because each level of government seeks to shift responsibility for service provision to another level, there are gaps in service provision to persons with HIV, complicated rules for eligibility, and many layers of bureaucracy to sort through. Many infected persons simply run out of energy before they are able to obtain services. The lack of integrated coordinated approaches where local workers have authority to respond appropriately results in constraints to innovative solutions and people with HIV suffer.

Municipalities are constrained by inadequate finances in providing services for persons with HIV. As most persons with HIV are located in a single area in each province due to the distribution of medical services, municipalities are at a disadvantage with provincial governments who like to institute provincial programs.

4.3 Existing Housing Options in Canada

Our national survey found 14 specialized housing projects targeted exclusively at persons with HIV/AIDS. These range from rooming house-type accommodation with no in-house support services to hospice accommodation with full medical staffing and all other relevant services. There are also four housing projects which are not targeted specifically at persons with HIV/AIDS but do include this group in its mandate. One of these four is a large private sector, non-subsidized inner city rooming house in Vancouver (Heritage House) which accepts persons with HIV/AIDS and provides advice about medical and social services. These 18 options, providing approximately 160 beds, are briefly described in Table 3.

In addition to these specialized housing options a number of organizations provide accommodation on a unit-by-unit basis. In Kingston, Ontario, for example, an apartment is maintained by the Kingston AIDS Project as temporary emergency short-term housing. Many AIDS support organizations have informal ways of finding temporary accommodation for people in immediate need, in addition, they help find longer-term accommodation if necessary.

Some municipal and provincial housing authorities are becoming more sensitive to the need to help provide immediate accommodation for persons with HIV/AIDS. Most have long waiting lists and complex bureaucratic rules about obtaining housing units when they become available. Few have yet to begin programs aimed at making other residents less paranoid about living with people with AIDS.

A. The Initiative by the Co-op Housing Sector

The co-operative housing sector has initiated a process aimed at educating its members about AIDS and at encouraging the 1,700 individual housing co-ops in the country to designate a unit or units for person(s) with AIDS. At its 1988 annual general meeting the Co-operative Housing Federation (CHF) of Canada passed a resolution to develop policies to assist member housing co-operatives to deal with AIDS-related issues. To this end, a report was commissioned, *AIDS and Housing Co-ops: Information and Guidelines* (1989), to inform members about such issues as

TABLE 3

Specialized Housing for Persons with AIDS in Canada

PROJECT	BEDS	DESCRIPTION
McLaren House Vancouver, BC	5	Independent living with residents responsible for their own cooking and cleaning; full-time coordinator provides counselling and does administration; funded by provincial Government.
Heritage House Vancouver, BC	12-17 *	Privately owned single room occupancy hotel provides independent living in 110 furnished private rooms; welcomes persons with HIV/ AIDS; full-time manager helps with access to medical and community services; no government subsidies; private donations.
Helmcken House Vancouver	32	Independent living in self-contained apartments (16 bachelor, 16 one-bedroom); no medical care provided; services arranged with outside agencies; one administrator and one half-time assistant; funded by provincial government.
Victoria Hospice Victoria, BC	7 *	Free-standing hospice offering counselling for patient and family, medical care, bereavement care and financial and social planning; 80 percent of staff are nurses; 18 full-time and 37 part-time positions and 248 volunteers; local fundraising activities.
Karos House Edmonton, AB	max. of 7	A residential care facility which also provides respite care when beds are available; does not provide active medical treatment; staff person available at all times; funding comes through Alberta Family and Social Services, Alberta Health and the Provincial AIDS Program.
Jocelyn House Winnipeg, MB	5 *	A free-standing hospice providing support and care for mentally alert persons in the last phases of life; patient care involves a variety of health care professionals, clergy, social workers and community workers; 50 percent of funding comes from fundraising activities; balance from the province and a per diem charge for residents.
Casey House Toronto, ON	12 & 1	A residence offering medical care in a home-like setting for people in advanced stages of AIDS; the first community-based hospice in North America exclusively for people with AIDS; offers a holistic approach to medical and care services; a multidisciplinary model of care delivery; funded by the Ontario Ministry of Health; fundraising maintains a respite care bed.
127 Isabella Toronto, ON	20 *	Offers rooming house style accommodation to low-income persons with severe housing problems who may or may not be HIV positive; no support services; funded by the Ontario Ministry of Housing.
McEwan House Toronto, ON	10	Provides supportive housing for men and women, sixteen years of age or older with special needs (mental or physical disabilities, homelessness); focuses on those who are HIV+ or living with AIDS; encourages personal empowerment, self management, and mutual support; staff on premises 24 hours; funded by the Ontario Government.

PROJECT	BEDS	DESCRIPTION
McEwan House Co-op Toronto, ON	5	Independent cooperative living; no staff on site; funded by federal co-op housing program and the Ontario Ministry of Housing.
Fife House Toronto, ON	5	A residence providing affordable housing; emphasis on independence and autonomy with respect to daily and long-term decision making; a part-time residence manager is on the premises; medical care is not provided.
Delta House Toronto, ON	4	A residence used largely as short-term housing; residents must be fairly independent and able to cope as in-house services are not provided; no paid staff, volunteer run; expenses are covered by sponsoring church congregations.
Barrett House Toronto, ON	5	A residential facility where staff are committed to fostering the personal independence of residents; staff include 3 full-time employees and 1 part-time employee and 4 to 6 volunteers; support and medical services are not provided on site; operating expenses provided by the Catholic church and the Ontario Ministry of Health.
Phoenix House Windsor, ON	3	A residence for persons who are ambulatory and able to live relatively independently but who have experienced difficulty finding affordable housing; there are no paid staff, volunteers help to coordinate services.
Bruce House Ottawa, ON	6	Provides a supportive environment for people incapable of living alone; no medical services on-site; four salaried employees and 60 volunteers; funded by Ontario Government and fundraising.
Maison d'Herelle Montréal, PQ	11	Residence for those undergoing a loss of autonomy; emphasis on maximizing quality of life and respecting privacy; 13 employees with a role for volunteers, family and friends; nursing service available; funded primarily by the Government of Quebec, Centraide and donations.
Maison Dehon Montréal, PQ	6	A group home for individuals who are independent but undergoing a loss of autonomy; residents are encouraged to participate in the "family situation" of the house; seven employees and 65 volunteers; operating costs are subsidized by local government.
l'Envol Montréal, PQ	9	A foster home for independent or semi-independent persons; medical services are not offered on-site; residents are encouraged to maintain their autonomy and participate in household activities; staff include two cooks, the director, and 25 volunteers; funded by the Catholic church and local government.
Transit Marc-Simon Montréal, PQ	10	Residence for persons with a slight loss of autonomy; private rooms; family atmosphere; 6 full-time employees (3 paid), 20 volunteers; managed by a local community group; financed primarily by government support.
Habitations Jean-Pierre-Valiquette Montréal, PQ	18	Individual apartments for those who are functionally independent at the time of admission; managed by a community organization; 5 employees; waiting list of 70 persons; funding from three levels of government and donations.

* Not specifically designated for persons with HIV/AIDS.

HIV transmission and prevention, AIDS and discrimination, the provision of a supportive housing environment for co-op members with HIV/AIDS and the creation of appropriate policies to assist a co-op employee with AIDS. This document encourages individual co-op boards of directors to educate co-op members about AIDS and risk reduction. Since each housing co-op is anindependent organization CHF has no direct authority to require member co-ops to put AIDS policies in place. It is hoped, however, that with the appropriate education the membership is more likely to support AIDS-related initiatives by individual boards.

In Metropolitan Toronto, as in other cities across the country, the boards of six housing co-ops have voted to grant persons living with AIDS a priority status when applying for membership allowing them to avoid long waiting lists and gain access to an appropriate housing unit. In some cases individual co-ops have entered into a contract with the AIDS Committee of Toronto (ACT). Under this arrangement the co-op itself is only responsible for the physical management of the unit and building while ACT is responsible for ensuring the member's access to appropriate services and for any arrears or damages incurred. Typically, ACT puts forward candidates for consideration, the membership committee decides on the individual's suitability, and upon approval the person becomes a member of the co-op. Similar waiting list priority arrangements are being made by individual housing co-ops in other parts of the country.

Because AIDS may affect an individual's ability to support him or herself many PWAs require a co-op unit which has a monthly guaranteed rent subsidy (the rent-geared-to-income program). An Ottawa co-op, recognizing that an individual's health may deteriorate over a period of time rendering him or her unable to work, makes emergency subsidies available to its members.

In 1989, a severe shortage of appropriate housing units for PWAs in Vancouver prompted a Skills Development Trainer for the Vancouver Housing Registry, together with members of the Vancouver Persons with AIDS Coalition, to approach individual co-op housing boards of directors with educational information and the suggestion that the co-ops might adopt persons with AIDS as a group, giving them priority status for available co-op units. Reaction to the presentations has been extremely positive. Between 10 and 15 co-ops have provided persons with AIDS priority status.

5. Housing Options

5.1 Essential Principles: Choice, Voice, Dignity

In light of the recent health promotion policy initiatives of the Federal government, and the professed support of "health promotion" at the provincial level, it is surprising that more has not yet been done around the issue of housing for persons with HIV. Health promotion is defined by the federal government as "the process of enabling people to increase control over and improve their health," a definition taken from the World Health Organization and enshrined in the Ottawa Charter for Health Promotion.[30] Embodied within the concept of health promotion are notions of social justice and equity, and social responsibility to allow people to fulfil their aspirations. Moreover, the Ottawa Charter identifies shelter as one of the basic prerequisites of health. If health is, in fact, a resource for daily living, then persons with HIV must be supported through fair and flexible housing policies that enable them to maintain control over and improve their health. Failure on the part of the government to respond to this issue will render meaningless the Framework for Health Promotion and increase the growing sense of cynicism that Canadians feel toward the state.

There are competing forces that must be considered in the provision of appropriate housing for persons with HIV infection in Canada. The individual's health status, the culture in which we live, and the political, economic and social contexts of communities across Canada are important factors in planning for the immediate and future needs for persons with HIV. Given the mandate for improved housing provision that follows from the Framework for Health Promotion, action to provide housing must be based upon clearly defined values and principles that honour the rights and address the needs of the individual with HIV, and support the community in meeting those needs. In our view, there are three such principles: choice, voice and dignity.

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30. Canada, Health and Welfare Canada (1986) Achieving Health for All: ,A Framework for Health Promotion, Ottawa: Supply and Services Canada; and Canada, Health and Welfare Canada *Ottawa Charter for Health Promotion*, Ottawa, p. 6

Persons with HIV must be offered a choice of housing options suitable to individual needs, circumstances, preferences and health status. Persons with HIV are not a homogenous group. The mere fact of a shared disease does not automatically mean that individuals share similar living habits, or that they would choose to live together. Most interviewees expressed the desire to live in their own homes, whether that be an apartment, a co-op, a residential hotel, a family home or a room in a shared living situation, for as long as they are physically and/or mentally able to do so. When independent living is no longer possible (or not desired), individuals must also have a choice of group care settings. When hospitalization is required, individuals ought to be offered a choice of ward-type, depending upon their needs.

Choice, too, must be offered to those who care for infected persons. Housing policies must recognize the significance of family and companionship relations, and make provision for couples, for individuals with children, for live-in caregivers and for families caring for infected persons. This recognition is particularly important with respect to (i) eligibility criteria for various programs, and (ii) provision of respite care. In the case of the former, those with HIV should not be penalized for being in relationships. Therefore, eligibility criteria for housing programs must not place undue burden upon others for maintenance or support. The number of hours of home care, for example, should not be restricted for persons in full- or part-time relationships with others, or for persons who receive support from family or friends. Housing for persons with children must adequately meet the needs of the child(ren) as well as those with HIV. Sufficient opportunities for respite care must be provided to live-in and family caregivers.

The voices of persons infected and affected by HIV must be listened to in developing housing policy options. Because they are not a homogeneous group, infected persons with different personal characteristics, circumstances and needs have to be heard and be made partners in the development of policies and options. Finally, all policy responses must respect the rights of all persons to live and die with dignity.

5.2 Points of Intervention

If persons with HIV are to obtain appropriate housing, aspects of Canada's housing system will have to change. Figure 4 provides a model of the possible range of housing system changes. There are four broad categories of actors (societal institutions) capable of addressing the housing needs of persons with HIV or, for that matter, any group or individual in need of housing assistance: the state; the private market; community-based and non-governmental organizations (CBOs and NGOs); and individuals and families. To varying degrees and in various ways all of these actors can take action to address (a) the housing needs of individuals with HIV, or (b) any of the specific groups with HIV, or (c) for the entire population of persons with HIV.

FIGURE 4

Points of Intervention For Housing System Change

Category of Need	Role of Actors			
	State	Private Market	Community	Individuals and families
Needs of Individuals with HIV	Providers of Payments, e.g. Vouchers, Cash Transfers, Subsidies	Responds to Demand in the Market	Activists; Providers	Activists; Providers; Consumers
Needs of Specific Groups with HIV	Regulators and Providers of Services and Payments; Enforcers of Standards	Providers of Congregate Care	Activists; Providers	Activists; Providers; Consumers
Needs of All Persons with HIV	Regulators and Providers of Services and Payments; Enforcers of Standards	No Role	Activists; Providers	Activists; Providers; Consumers

The principles espoused of respecting the choice, voice and dignity of persons with HIV means that there is not a single response which is appropriate for all persons. There are basic citizenship rights which are shared with all Canadians, and some which are particular to persons who are disabled by HIV. The need for appropriate housing and access to medical and support services is common. Specific groups of persons with HIV also share some characteristics such as the needs of injection drug users for housing and support services which are appropriate to their particular needs. Likewise, women with children share the need for support for their children as well as themselves. The needs of specific groups can serve as a catalyst for appropriate action for government intervention, for market segmentation by the private sector, and for community activism on behalf of identified groups of persons with HIV. In the final analysis, however, it is the individual and his or her family who lives and dies in the housing provided. The needs of

individuals vary over the course of the disease, by individual preference and lifestyle and geographic location. Policies and programs which are established to meet the needs of specific groups and/or all persons with HIV must take into account the need for flexibility and responsiveness to the local and specific needs of individuals.

The Role of the State. The socially assisted non-market housing sector in Canada -- public housing, public and private non-profit housing, and the co-operative housing sector -- is very small and is already incapable of meeting existing severe housing needs, let alone the new needs of persons with HIV. State intervention, in the form of regulation and/or assistance to the private sector, the community-based non-profit sector, and individuals and families is required if housing needs are to be effectively addressed. Indeed, the state must play the lead role in this provision. None of the other actors are capable of making significant contributions to housing without support from the state (defined here as the federal, provincial and municipal governments and associated agencies and offices).

A further role for federal, provincial and municipal governments is inevitable. The state must use a combination of its available methods, which range from exhortation and moral suasion, to direct expenditures, tax expenditures, taxation, regulation, standard setting and public provision/ownership. The state can provide resources to community-based non-profit associations and agencies to develop and operate housing, forms of assistance can be provided to individuals and families, and regulations, taxes or subsidies can be used as incentives for appropriate private sector activity.

The role of the state is to ensure that when the market does not work that there is an intervention to protect the basic rights of the citizen. The market does not work when people have no money to participate in the housing market, or are faced with rejection of their attempt to participate due to discrimination. Market intervention can take place on the supply side by government acting as a provider of social housing, regulator or enforcer of standards; or on the demand side by providing assistance in the form of vouchers, cash payments, and/or subsidies to people to participate in the housing market.

The Role of the Private Market. The private sector role is limited to responding to the effective market demand for appropriate housing generated by people with money. One exception -- the only one found by our survey of the nation -- is Heritage Hotel in Vancouver. This is a privately owned apartment building with 110 single occupancy rooms which not only welcomes persons with AIDS but provides social and emotional support and a referral service. There are generally 12 to 18 persons with AIDS living in the building. When the local newspapers began to run

occasional feature articles on the building and its owners, a number of community groups and individuals made in kind donations of meals, and baked goods, and financial contributions for the persons with AIDS in Heritage Hotel. No government subsidies are involved.

It is not realistic, however, to expect more of this to occur spontaneously within the private housing sector. The private market responds to demand, and without the incentive of a potential profit it does not act. It is easy to stimulate and predict the reaction of the private market: it responds to profit. In the private market in general, if there is no incentive then there is no response. The response of Heritage Hotel is altruistic, and an anomaly in the private market.

The private sector could play a role in meeting the housing needs of specific groups with HIV through extended care and congregate care housing facilities -- as it does with the elderly population. Examples of this type of response are beginning in the United States through the Wanaque program in New Jersey which has developed a model for AIDS care which has a dedicated congregate care facility. This corporation has had extensive experience in developing seniors congregate long-term care facilities[31] and have organized the facility around a nursing care model.

Many believe that if government subsidies are involved the non-profit sector would provide better and more cost-effective service. It is difficult to predict which approach can provide the most appropriate response to the housing needs of persons with HIV without examples in the private market to evaluate.

The Role of the Community. The community of interest, both formal and informal organizations of persons concerned about persons with HIV in the non-profit non-government sector has two main roles, those of being actual providers of service, and advocates or activists to encourage other sectors to deliver needed services.

Community-based non-profit organizations which have the support of their constituent groups hold the most potential for meeting the housing needs of persons with HIV infection. These groups tend to know their communities and are usually best able to define appropriate local solutions in co-operation with the persons affected and the organizations which represent them. The

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31. . A. Minnefor, S. Lazovitiz, R. Mondrone, J. Spector & A. Stern (1991) *A Nursing Home Model for Care of Aids Patients: A Three Year Experience*, VII International Conference on AIDS, Florence, Italy, June 16-21, 1991.

identification of needs, design of appropriate responses, and implementation and operation of actual housing resources are well within the range of the community's capacity to respond.

The community may also be defined as the geographic community -- persons who live in the same villages, towns or city neighbourhoods as persons with HIV. While responses by geographically-based communities are often compassionate and supportive, the local community response can also be negative (when NIMBY attitudes prevail, for example). Where community groups have formed to exclude persons with HIV from their geographic areas some mechanism for resolving conflict and protecting the rights of the infected individual must be found.

For community action to work there must be a combination of action, commitment and money. The necessary financial resources required to sustain this effort can come from different levels of government and/or from private fundraising activities. AIDS service organizations have demonstrated a commitment to improving the conditions which negatively affect persons living with HIV. The private sector has a role in supporting community action by making direct donations or lending their staff to organizations working toward a solution for housing problems for persons with HIV.

Partnerships between government, CBOs and NGOs, and private contributors (charitable organizations as well as individuals) are necessary and desirable in working towards solutions for housing for persons with HIV. Collaborative partnerships take time, energy and resources to work. The management of conflict that will inevitably arise among the partnership must be considered in advance and strategies adopted to resolve conflict.

The Role of Individuals and Families. Individuals and families are consumers of housing, can be providers of housing and have been effective in advocating for needed housing and allied services. As citizens, individuals have rights to basic services in Canada and a responsibility to identify when their citizenship rights are abrogated. For persons with HIV and their families this means understanding that they are entitled to live with freedom from discrimination based upon disability status, and complaining when they experience discrimination. While every citizen has the responsibility to ensure that their rights are respected, persons who are not competent to exercise their rights may also find it difficult to protect themselves from discrimination. This extra burden of citizenship responsibilities means that many individuals and their families require the support of organizations concerned for the protection of human rights, and government who must act to enforce the rights of citizens.

The problems persons with HIV are having obtaining appropriate housing will only be resolved by changing some elements of Canada's housing system. This can only happen if all four

categories of actors co-operate. Though the housing problem is directly connected to poverty and inadequate income, at present there simply is not enough appropriate housing stock available in the locations where it is required. Housing for persons with HIV is both an income maintenance problem and a housing stock problem. It cannot be solved by action in one area alone. Collaboration is required in order to meet the housing needs of persons with HIV with respect for their choice, voice and dignity.

5.3 Housing Options Model

As defined in this report, *appropriate housing* is housing that is suitable to the individual's circumstance and depends upon the individual's specific needs. It maximizes choice, independence, and a sense of belonging to the community. True choice means that services must be available that are appropriate to the person's particular situation. Housing, as a physical structure, and the social support services required by an individual or a family, cannot be considered separately. Thus, if the desired state is to maintain the individual in his or her own home, what are the services that are required to facilitate that choice? These issues are particularly difficult for persons with HIV, whose health status and level of physical and mental competency is subject to continual change. Housing-related support needs change as the disease progresses. Just as there is a continuum between independence and dependence, there must be a continuum of care linked to appropriate housing for the person with HIV. As this disease does not have an orderly linear progression, the continuum of care must be flexible and responsive to the changing needs of the individual.

As outlined in Figure 5, there is a continuum of housing options based on the physical and mental competency of the individual, that is, the ability of the individual to exercise choice. Self care requires a high level of competency and does not require any special form of housing. It does require that the housing system make available a full range of appropriate options which are adequate, accessible and affordable.

For persons with reduced competency a higher level of care is required. Group homes, extended care facilities and specialized hospices provide the range of care required, though there are presently few such options available in Canada. In addition, there is the problem of locating these special housing options. Neighbours (often entire neighbourhoods) actively oppose the location of a group home or hospice. For those who have minimal competency in exercising choice, and who do not want or can not find room in a hospice, there is no choice but the hospital.

FIGURE 5

Housing Options for Persons with HIV Infection Related to the Individual's Abilities and the Level of Care Required

Levels of Ability for the Individual to Exercise Choice	Levels of Care	Type of Housing
Most Able	**SELF CARE** • **Individual (no support)** • **Supported** • **Family Support** • **Foster Care**	The *self care* options usually take place in single and semi-detached houses and in condominium or rental apartments. The nature of the local housing market (vacancy rate, housing adequacy, availability and affordability) is one important factor. Other factors include access to medical and support services.
Less Able	**GROUP CARE** • **Group Homes** • **Extended Care Facilities** • **Hospice**	The *group care* options require the conversion of an existing house or small building, or the construction of a purpose-built facility. Purpose built buildings are not part of the regular housing stock due to their specialized features. Without this form of housing available in a community, there is no intermediate support between self care options and hospitalization, the most expensive form of care.
Least Able	**HOSPITAL** • **General Ward** • **Palliative Ward**	These options do not require housing stock. The person is out of the housing stock and in a specialized institution (the hospital).

5.4 Policy and Program Options

Public policy and programs are required if the housing needs of persons with HIV infection are to be met. Policy is a statement about a course of action and refers to the principles that govern decision making about a particular objective. Programs are specific actions designed to implement policy objectives.

The federal government in co-operation with provincial and local governments must adopt a housing policy for persons with HIV that can be tailored to local conditions. The policy must be prepared in conjunction with the people affected and the organizations which represent them. Those affected must have a voice in the decisions and a choice in the solutions which affect them.

Though it is a *housing* policy which is required to address housing needs, it is not a policy limited solely to housing as physical structures. Housing programs in the traditional sense are not appropriate. Housing for persons with HIV involves health care issues and programs, social service issues and programs, as well as housing issues and programs. Health, social services and housing policy and programs must be integrated. These three policy domains have always been separate, something which is increasingly unacceptable and is especially problematic in the case of HIV infection. In the United States, social service and housing professionals have begun to address this problem and the Urban Institute in Washington, D.C. has sponsored a major study of the problem.[32]

The objective of a national and the regional housing policies for persons with HIV is to integrate the housing and related social service and health policy areas to develop programs which maximize choice and local input, and maintain dignity. The housing options model in Figure 5 identifies different options based on the ability of an individual to exercise choice:

- those who are most able to care for themselves if appropriate support is available;

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32. See: National Association of Housing and Redevelopment Officials and American Public Welfare Association (1989) *Findings, Initiatives and Recommendations: A Report of the Joint Advisory Panel on 'The Housing Component in Welfare Reform' of the National Association of Housing and Redevelopment Officials and the American Public Welfare Association*, Washington, D.C.: NAHRO; Newman S.J. and A.B. Schnare (1989) "Reassessing Shelter Assistance: The Interrelationship Between Welfare and Housing Programs," Chapter 6 in *Housing Issues of the 1990s*, S. Rosenberry and C. Hartman, eds., N.Y.: Praeger, pp. 121-149. Newman, S.J. and A.B. Schnare (1988) *Subsidizing Shelter: The Relationship Between Welfare Reform and Housing Assistance*, Washington, D.C.: The Urban Institute Press.

- those less able to care for themselves requiring a great deal of housing, social service and medical support provided in group care situations; and

- those least able, usually unable, to care for themselves and need to be hospitalized.

Each group requires a different housing policy and program response. Temporary shelters are not included in the range of options presented. Shelters for the homeless are not housing. They are temporary substitutes for appropriate housing and as such are in the realm of emergency responses, and are not a *housing* option.

A. Housing Options Based on SELF CARE

For those who are most able to exercise choice, which is by far the majority of persons with HIV, the range of options includes: individual self care without support assistance; individual self care with some support; family support for individuals; and foster care support for individuals. In terms of housing stock, it is this category of self care options that utilizes the majority of Canada's existing housing stock: detached and semi-detached houses and condominium and rental apartments. This includes both private sector and social housing. For example, apartment complexes which have several persons with HIV who have deliberately chosen to live within the same building uses existing housing stock. The nature of the local housing market (vacancy rates, housing adequacy, availability and affordability) is an important factor in determining whether persons with HIV can access the housing they need. However, the *location* of the housing is also an important factor. For many persons with HIV, the housing must be located near or within a reasonable commuting distance of the required medical and support services. This is particularly the case for persons with AIDS as much of opportunistic infection prevention relies upon regular prophylactic treatment.

Independent self care. Housing policy and program options for individuals who can take care of themselves, at least while they are in good physical condition, need to be focused on and can be limited to various types of regulations. Government must ensure that impediments to the ability of individuals to care for themselves are not allowed to arise and, if they do, are not allowed to persist. Three forms of security must prevail if a person with HIV is to maintain independence: tenure security, employment security, and physical security (a safe and healthy living environment). All people should have these. Persons with HIV are among those most likely not to have these forms of security to begin with, especially if they are an injection drug user, sex trade worker or experience discrimination due to their sexual orientation or gender. If

it is known they are HIV positive, their housing, employment and even physical safety could be affected by discrimination.

If in the housing market landlords are found to be discriminating against people because they are HIV positive, appropriate action must be taken and penalties imposed. This also applies to public housing authorities and non-profit and co-op housing organizations.

The major determinant for maintaining independent self care in appropriate housing is job security. Freedom from discrimination not only applies to the housing market but also the job market. Without an adequate income, self care without outside financial support usually becomes impossible.

A third aspect of independent self care relates to physical safety. The housing unit itself as well as the neighbourhood around it must be safe and healthy. Most of the persons with AIDS and most of the housing located convenient to medical and social services in cities such as Vancouver, Toronto and Montreal are in inner city areas which tend to have mixed quality housing stock -- very expensive gentrified housing or lower quality which tends to be less safe than other residential areas.

One aspect of the disease which sets people with HIV apart from persons with other disabilities is the nature of the disease progression. HIV does not have a uniformly linear progression, and thus persons with HIV may be able to function for the most part in the self care domain with support care required *temporarily* during bouts with opportunistic infections. There is a need to be able to move back and forth between levels of support, thus policies and programs must be flexible and responsive to the needs of the individual in their community and recognize that the situation is not static, but dynamic.

Self care with support. This category of care refers to the range of support services that can be moved into the home in order to maintain a person with HIV in their own home. Examples of these services are: home help which includes domestic services such as cooking, shopping, cleaning, laundry; personal services such as financial services (bill paying, banking), personal hygiene, assistance to attend medical appointments, and maintaining communication between the individual and his or her family and community; medical support services from the administration of therapies and drugs to specific treatments; and finally palliative care. The level of support that is required may vary from a few hours per week to full-time care. If the person desires care in their home, and the home is appropriate, every effort should be made to meet with dignity the needs of the individual.

Responsibility for policies and programs to achieve self care with support options are primarily located with health and social services ministries of the various provincial governments. The lack of coordination between these two departments can make the access to services and the maintenance of needed services difficult for individuals who do not meet previously established program guidelines. In both jurisdictions there is a reluctance to take responsibility for the total needs of the individual, and therefore the ability to integrate services to meet the needs of any one individual is limited. The consequence of this lack of integration is felt by the individual with HIV who may require intensive support for short periods of time and then very little or no support for long periods thereafter. Without intensive short-term support when needed, the individual can lose the security of their own home by not being able to care for themselves in it, or maintain themselves financially. This loss is cumulative in other areas, as the individual must often continue to accept accommodation that is not of their choice once they are well because they have lost their original housing. Losses can contribute to the decline of the individual who loses his or her freedom to exercise choice but not their capacity to do so.

Family Support. Family supported housing refers to the situation where the individual lives with his or her family of origin or family of choice. This may mean that the individual is in a shared living situation with his or her family, or that the family performs the support roles or some portion thereof, as referred to above. Access to support services from the medical and social services sphere is crucial to families for successful support of the person with HIV.

The housing stock is again the private market with some variation. First, policies that will allow the individual with HIV to contribute a fair rent or room and board to the family can assist the family in meeting the associated financial burdens experienced in caring for the person with HIV. Policies are needed which permit the individual to contribute fairly to the expenses of the family home to both preserve the individual dignity of the person with HIV and to assist the family in supporting the individual.

Many families are willing to provide the necessary care, especially if there is adequate financial support to do so, however families also require relief or respite care. Respite care is a service that allows the family to have temporary relief from the day to day care needs of the individual. With respite care families can take holidays, attend to other family needs, and provide the cushion in situations where the only alternative might be hospital. Respite care can mean that support services generally performed by the family are performed temporarily by someone else, or that there is another physical space where the individual can stay temporarily.

Housing is not a stand alone issue. Without adequate support services the provision of a physical space is inadequate to meet the needs of individuals and their families to maintain self care with

family support. Families cannot sustain the level of care required to allow a person to remain at home without consideration of the financial burden, and the need for respite care. Flexible policies which can be adjusted for the needs of the individual and their family are essential to preserve this option for persons with HIV.

Foster Care. This option has many of the same features of family care with support. Foster care is generally organized by government or voluntary societies and regulated by government. There is regular payment received for the care offered and individuals may be placed with foster families by an intermediary.

The housing stock is in the same realm as family care -- the private market with the foster family owning or renting the home and then providing space to individual persons requiring care.

Foster care is a well-developed program across Canada for children who require care. It is modelled on the belief that children should be in a home that resembles, as much as possible, the family home. The idea is less well-developed for adults, however there are some positive individual examples across Canada where churches and voluntary organizations (and in Quebec, government) have organized foster care for adults.

Extending availability of this option could be achieved through many of the existing resource systems to include adults with HIV. Ensuring adequate supply of this resource is dependent upon finding the right price to attract individuals to offer these services. In rural areas this option may be viable for individuals who require care as long as there are adequate medical and support services to maintain the person in the geographic community. Foster care allows for a home-like atmosphere, and greater flexibility to meet the individual needs of persons with HIV than institutional settings.

B. Housing Options Based on GROUP CARE

There must be an intermediate housing and support option for persons with HIV which lies between self care and hospitalization. As Figure 5 indicates, this option is for persons with HIV who are less able to exercise their own choice. Group care options should help further maximize choice and maintain dignity while avoiding the most costly and often less desirable option of hospitalization. The group care option requires the conversion of an existing house or small building, or the construction of a purpose-built facility. Purpose-built buildings are not part of the regular housing stock due to their specialized features. They can range from good quality affordable and appropriate accommodation without any special social or medical services provided,

to facilities which offer virtually all necessary services, approaching the level of care in a hospital. Examples of specialized housing facilities which exist for persons with HIV are contained in Table 3. There are approximately 155 specialized group care spaces for persons with HIV across Canada. There are an estimated 30,000 to 50,000 persons infected with HIV in Canada [33] (see section 3.2 for a detailed discussion of seroprevalence estimates). The gap between what is currently available and what is needed at the group care level is significant. Pressure to create specialized resources appears to be as a result of the inadequate response to the needs of individuals to maintain themselves in their own homes.

It may not always be financially viable to offer group care facilities in smaller communities. Such care depends upon a critical number of persons with similar care needs being interested in sharing living situations.

Group Homes. This option describes the arrangement where individuals with HIV live in one building where some facilities and activities are shared with other residents of the home. Individuals may have private bedrooms and baths, generally however, kitchen and laundry facilities are shared and often baths as well. The majority of group homes provide services for individuals such as meals, laundry and assistance in daily living tasks as necessary. The policies and programs required to initiate group homes are within jurisdiction of several ministries and levels of government. The initiative to start a group home is often from community-based organizations. Funding for building or renovating a special purpose facility must be raised or borrowed. The capital costs of special purpose facilities is the first major expenditure category. The operational costs for a group home facility can be a significant ongoing expense. Assistance may be required to supervise the renovation or construction of these purpose-built facilities when the group who initiated the response do not have adequate experience to develop housing. Zoning for group homes may require community approval and/or changes in the existing bylaws to allow construction of a specialized resource. This may require the active involvement of local planners to work with the group home people as well as the community where the proposed group home will be located. Ignorance and prejudice about HIV can unleash a powerful resistance to the group homes. The NIMBY syndrome is familiar to most groups trying to develop housing for persons with disabilities.

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33. . S.A. Marion and M.T.Schechter (1991) *An estimation of the number of persons in Canada infected with Human Immunodeficiency Virus*, Report to the Minister of National Health and Welfare, Ottawa.

Extended Care Facilities. This option provides nursing care, and daily assistance to accomplish the tasks of living. The level of care provided varies from care for persons who are ambulatory but unable to perform some essential tasks for themselves to those persons who need constant care and supervision. Extended care facilities are generally regulated by the provincial government and may be paid for privately, through private insurance, or provincial payments that are cost shared with the federal government. The extended care facilities may be government operated, run by a non-profit society or by a for profit corporation.

The majority of existing extended care facilities are serving the needs of elders who are not able to care for themselves or be cared for by their families or community. Most have waiting lists and many waiting lists for extended care facilities exceed two years. A two year wait for a persons with AIDS is unacceptable, and not a solution to housing problems.

Persons with AIDS who have dementia have the greatest need for extended care services. The level of care required is substantial to manage individuals whose ability to make decisions is impaired by the disease.

Hospice. Specialized housing for persons who are imminently terminally ill is the main purpose of a hospice. The majority of hospices in Canada do not discriminate against persons with HIV and many have developed specific policies for persons with HIV. In general people enter a hospice 30 - 90 days before their death. While the hospice model works to make people comfortable in their last days, admission is delayed as long as possible to maintain a hopeful outlook. An innovative program for home-based hospice care has been developed in Victoria, B.C. A travelling hospice team provides care and pain relieving drugs to patients in their home environment, as well as training caregivers in care and pain management techniques and emotional support.

In order to have hospices there must be adequate financial support to operate a facility. Supportive relationships with the medical establishment are essential so that when necessary there is appropriate back up to the hospice.

C. Hospital Options

When a person requires the highest level of medical attention on a long-term, or terminal basis, the issue ceases to have a housing aspect. The person is out of the housing stock and into a specialized institution. A problem arises when the lack of appropriate housing for individuals with HIV to go to when they could be discharged safely means that hospitals are turned into housing.

At the other end, the lack of appropriate housing can exacerbate health conditions to the extent that people require hospitalization. In both cases the lack of appropriate housing can have unintended consequences for hospitals, and contribute to the pressure on already strained resources to provide hospital beds.

This research has found that housing policies and programs for persons with HIV are urgently needed in Canada. This report identifies a number of issues associated with HIV and housing, and suggests a range of policy options. We believe that it is imperative that housing policies and programs be developed, and that these be guided by the principles of choice, voice and dignity. Canadians deserve no less than this.

6. Recommendations for Action

Appropriate housing for persons with HIV is an urgent and pressing problem that demands a coordinated and collaborative response between all levels of government (federal, provincial and municipal) and multiple departments including housing, health, and social services to work with community representatives to solve problems and create solutions. Partnerships between governments, AIDS service organizations, organizations of Persons Living with HIV/AIDS and the private market sector must be formed to plan and develop responses to meet the housing needs of persons with HIV. The housing problems of persons with HIV cannot be solved by adjusting programs at the margins. There needs to be a multi-pronged approach to the multi-faceted problems that individuals with HIV face in finding appropriate housing -- housing that is adequate, accessible, affordable and available. This section outlines the crisis areas and immediate needs of persons with HIV across Canada and suggests principles and guidelines for local response to identified issues.

The stories of individuals with HIV, their partners and families, the concerns of individuals in various service organizations and government officials working in communities all emphasized the lack of integrated responses and the paucity of the choices available to house persons with HIV. While each story is different and each community presents unique challenges and opportunities, some common themes emerged. The principles of choice, voice and dignity mean that the actual solutions to problems must be developed on a local level with the participation and support of the relevant actors and decision makers in the local community. Some of the challenges to solving the problems of housing for persons with HIV are not merely the concern of local communities. The larger jurisdictional issues demand that provincial and federal governments also lend support to local communities in a mutual effort to meet the housing needs of persons with HIV in their home community.

The federal government must take a proactive role in stimulating response to local needs by working with community groups and governments at the provincial and municipal levels to solve the immediate and urgent housing needs of persons with HIV *in their own communities*. As 95 percent of Canada's housing system is market driven and only 5 percent is social housing, the urgent needs of persons with HIV for appropriate housing will not be solved by program

adjustment within the social housing sector. Solutions to these housing needs of persons must recognize Canada's current incomplete housing system and assist persons with HIV to participate in the private market sector.

There are three groups whose needs are at crisis proportions: injection drug users, particularly young people; mothers with children; and persons who were impoverished before their diagnosis of HIV infection. Also, the majority of persons with HIV have an increased need for support services at the time of transition from one level of care to another such as the move from supported self care to group care. Without housing options, persons with HIV are forced to move into hospital which is the most expensive type of care and an inappropriate form when used to solve a social need for housing rather than a medical need.

The category of persons who are the poorest served by existing services are the injection drug users, particularly young injection drug users. Although there are pockets of excellent people providing much needed services, the overall picture for these young people is bleak. Immediate action is necessary to provide housing for street persons who have tested positive. There needs to be housing available that is not dependent upon residents becoming non-users of drugs or alcohol. Likewise, the combination of substance abusers with those who are attempting to abstain from drugs or alcohol is incompatible. While in general scarce resources are best used to serve persons who have demonstrated the desire to enter into a recovery program, it is not so in this case. There needs to be housing for the injection drug user to both protect the individual's personal health as well as to reduce the risk of further HIV transmission to the community. By providing a location from which the individual can receive services and access resources to protect their health, the injection drug user is stabilized in the community.

Women with children are underserved and their needs are underfunded. There is little or no recognition of the high cost of meeting the multiple needs of mothers with HIV and meeting the needs of their children. Housing access in this case is limited by additional factors related not only to the mother's needs for prophylactic medical and support services but also by the needs of the children for child care, schooling and support services. These limitations further restrict the available market for mothers with HIV and almost invariably adversely affects their ability to seek bargains in the market place. Mothers with children have even fewer opportunities to trade-off price for location or adequacy of accommodation.

Poor people who learn of their HIV status face many problems when seeking to stabilize their health. Those persons who have been living in housing situations which are characterized as inadequate (unsafe, no tenure, cold, draughts, unhygienic), are faced with an immediate need for appropriate housing and in general have inadequate financial resources to secure it. The situation

is even more critical for persons who are homeless at the time of diagnosis. Both impoverished and homeless persons require immediate support to move them into stable and secure housing.

Persons with HIV in transition are in need of substantial forms of support. Transition in this case may be either medically-related (ie. learning of one's seropositivity, change in status from asymptomatic to symptomatic, and diagnosis of AIDS) or housing-related such as moving from supported self care situations to group care. There are many overlaps between these two events as persons who experience change in their health status also by necessity experience change in their living situation. There is an immediate need to provide stabilizing services for individuals in transition to assist them in moving smoothly from one stage to another.

6.1 Appropriate Housing

Appropriate housing for persons with HIV has been defined here as housing that is adequate, accessible, affordable and available. The delivery of appropriate housing is dependent upon each factor being present. Affordable housing that is not adequate is not appropriate, nor is accessible housing that is not available when needed. In order to insure that persons with HIV are appropriately housed the following issues must be addressed recognizing that each factor is intertwined with the others.

6.2 Adequate Housing

Standards for housing persons with HIV include housing that is warm, dry, easy to keep clean, safe from violence and secure in tenure. These standards promote and protect the health of the individual with HIV and the availability of adequate housing for persons with HIV reduces the risk of HIV transmission in the community.

Standards of Adequacy

National standards to describe adequate housing should be developed by representatives of AIDS service organizations, organizations of Persons Living with HIV/AIDS, governments, and the private sector.

Standards to ensure adequate housing for persons with HIV must not be used to evict tenants, or move residents against their will.

Resources to upgrade the housing of individual residents to meet national standards of adequate housing should be made available through local AIDS service organizations to assist individuals to stay in place when desired.

Standards of adequacy should govern the development of new housing for persons with HIV.

The enforcement of standards of adequacy for housing for persons with HIV should be a local responsibility.

Standards of adequacy should reflect the degree of care required by the individual at the various points of their illness.

6.3 Accessible Housing

Accessible housing for persons with HIV is housing that has level entry or assisted entry, space for a caregiver to spend the night when required and is close to the necessary medical and support services. Access to services is dependent not only on information getting to the potential user about the service but on concrete action being taken in order to ensure that services are truly accessible. As one interviewee stated:

> *"Control over the delivery of housing and support for people with HIV/AIDS should be in the hands of those who are as close to the need as possible ... ideally, perhaps, persons with HIV/AIDS themselves."*

The location and satisfaction with available health and social services for persons with HIV will in large measure determine where individuals live in the community.

Integration of Services

Services for persons with HIV must be integrated at the service delivery level rather than forcing the individual to adapt to various service structures.

Services for persons with HIV must include accessible medical and support services to allow individuals to maximize their choice of location in the community.

Home Care Support

Home care support hours must be flexible to meet the changing physical demands of persons with HIV infection in order to support them in their chosen environment.

Home care support services must consider the needs of families and partners and not penalize caregivers by refusing or reducing home support services to persons with HIV who are sometimes cared for by family and/or friends.

Additional Services

Support services must include substance abuse services for persons with HIV who are injection drug users.

Medical and support services must deliver services to HIV positive injection drug users who are not prepared to enter substance abuse recovery programs.

Mothers with children need support to care for their children in the form of additional child care, home care support and transportation money so that their children are adequately cared for during periods when the mother is experiencing fatigue or other symptoms typical to HIV/AIDS.

Impoverished or homeless persons who receive a diagnosis of HIV need immediate support to locate or relocate into appropriate housing.

6.4 Affordable Housing

The diagnosis of HIV can signal the beginning of a slow or precipitous decline into poverty. The rate of that decline is dependent upon the individual and their circumstances. The price of being HIV positive varies across the country depending upon the cost of drugs and health services. However, for most people there is an additional financial cost to being ill and a reduced capacity to earn money to pay for the services required. The majority of persons who are diagnosed as HIV positive have been single men who are in their mid-thirties. In general, individuals in this cohort have not had the opportunity to amass savings or assets sufficient to be self-sustaining through to the end of their illness.

Disability Pension

The federal government should create, fund and distribute a disability pension scheme payable to all persons with HIV infection.

New Housing Funding

Adequate funding to initiate and develop new housing for persons with HIV should be made available by the federal government at the local level to consortiums of community and consumer organizations, governments and the private sector.

Income Assistance

Income assistance payments to persons with HIV infection must reflect the true costs of supplying adequate housing in the local market.

Income assistance payments to persons with HIV infection must reflect the additional costs associated with the disabling conditions related to HIV infection such as drugs, health services, food and transportation costs.

Income assistance payments to mothers who are HIV infected must reflect the additional costs of caring for dependent children when the parent is disabled.

Income assistance payments to persons who are homeless or who have been receiving income assistance for long periods must reflect the additional requirements to stabilize themselves in appropriate housing.

6.5 Available Housing

Canada lacks a complete housing system and the majority of persons with HIV infection are competing for scarce low-income rental housing in the inner cities of Vancouver, Toronto and Montreal where they live in order to have access to available medical and social services. There is a lack of congregate care facilities and the result of this lack of appropriate housing forces many persons with HIV to stay in hospital longer than necessary which reduces the extent to which resources can be applied elsewhere.

Reduction of Waiting Lists

Immediate action must be taken to reduce the waiting lists for persons with HIV awaiting entry into supported self-care facilities, congregate care facilities and palliative care or hospices.

Transition Houses

Housing for substance users who are HIV positive must be made immediately available.

Transition housing for persons requiring short-term respite care needs to be available to serve persons with HIV moving from one housing situation to another.

Information and Referral Services

Local housing information and referral services for persons with HIV infection is needed.

Housing information and referral services should be given authority to exercise priority in securing market housing for persons with HIV.

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Appendix

A. Contact Letter

B. Text of Interview Schedule

Appendix A: Contact Letter

June 28, 1990

Dear,

The UBC Centre for Human Settlements is conducting a study called ***Housing for Persons with HIV Infection in Canada: A National Study of Housing Issues and Options*** funded by National Health and Welfare. The aim of the study is to describe the present housing situation and needs of HIV infected persons, the range of current housing and living options across Canada, and to recommend housing options to meet present and future needs (see attached summary). the documentation and recommendations should provide useful information for advocacy groups, municipalities, and provincial governments attempting to meet the demand for housing for HIV positive persons.

The purpose of this letter is to ask for your support by contributing your knowledge of the local housing situation. We would like you to provide us with two types of information:

1) names, addresses and phone numbers (where possible) of key organizations, groups or individuals in your community who may be able to assist us with understanding and describing the available housing for HIV infected persons and the current needs. We are looking for representatives of community organizations, government agencies, voluntary or self-help groups or individuals. The emphasis should be on the key players and/or decision makers; and

2) copies of any published reports, newspaper articles or similar material on unique or interesting options for housing or care for persons with HIV infection, either planned or operating in your city.

Your response would be appreciated, either by collect phone call, letter or fax, by July 27.

This information will be used to set up appointments for interviews with key people. The purpose of the interviews, which should take place in the fall, is to allow us to obtain a picture of the range of services and options available, major issues, as well as to prepare case studies on unique living situations, housing options or approaches to housing.

If you have any questions or comments about the study, please contact myself or Margaret Eberle at (604)822-5254. Thank you in advance for your cooperation and support. We look forward to meeting you in the fall.

With Best Regards,

Sharon Manson Willms, Ph.D.
Faculty Associate, Centre for Human Settlements
Assistant Professor, School of Social Work

Encl.

12 Juillet 1990

Chère M.,

Le Centre d'Etude sur les Etablissements Humains de l'Université de la Colombie Britannique conduit actuellement une étude appelée ***Logement des Personnes Infectées par le VIH au Canada: Enquête Nationale sur les Problèmes de Logement et Leurs Possibles Solutions***. Cette étude, qui est financée par Santé et Bien-Etre Social Canada, a pour but de décrire la situation actuelle à l'égard du logement et les besoins des personnes infectées par le VIH, de regrouper la variété des solutions qui ont été adoptées au Canada pour répondre à ces besoins et enfin de recommender des solutions susceptibles de satisfaire les besoins présents et futurs de cette population (voir le résumé ci-joint). La documentation et les recommendations apportées par cette étude constitueront un recucil de données que pourront immédiatement utiliser les groupes de revendication, les municipalités et les gouvernements provinciaux qui tentent de répondre à la demande de logement des personnes porteuses du VIH.

Le but de cette lettre est de vous demander de bien vouloir nous aider dans cette entreprise en partageant avec nous les connaissances que vous avez de la situation du logement dans votre propre communauté. Nous avons fait de notre mieux pour que cette enquête ne necessite qu'un minimum de temps de votre part. Nous vous demandons de bien vouloir nos donner deux sortes de renseignements:

1) Les noms, adresses et numéros de téléphone (si possible) des principales organisations, groupes ou individus de votre communauté susceptibles de nous aider à comprendre et à décrire les besoins de logements des personnes infectées par le VIH et les solutions qui sont offertes actuellement. Nous recherchons des personnes représentant des organisations connunautaires, des agences gouvernementales, des groupes de volontaires ou d'entraide, ou encore de simples particuliers. Priorité devrait être accordée aux personnes qui jouent un rôle décisif dans la situation ou qui occupent des postes à responsabilité.

2) Les copies de toute publication, article de journal ou source d'information similaire décrivant des solutions uniques ou originales ayant pour but de répondre aux besoins de logement ou de soins des personnes infectées par le VIH soit à l'état de projet, soit fonctionnant actuellement dans votre ville.

Nous vous remercions d'advance de bien vouloir nous répondre soit par téléphone en P.C.V., soit par lettre, soit par télécopie avant ou le 27 juillet au plus tard.

Les renseignements que vous nous soumettrez seront utilisés pour organiser des interviews avec des personnages-clef. Le but de ces interviews, qui auront vraisemblablemeut lieu cet automne, est de nous permettre d'obtenir un tableau d'ensemble de la variété des services et des solutions qui existent actuellement en matière de logement, d'identifier les problèmes majeurs et de preparer des descriptions de cas individuels représentant des arrangements, solutions ou approches originaux face au probléme du logement.

Si vous avez des questions ou commentaires sur cette enquête, n'hesitez pas à me contacter en personne ou à contacter Margaret Eberle au (604)822-5254. Merci d'avance de votre soutien et coopération.

Dans l'attente de vous recontrer cet automne,

Sincères salutations

Sharon Manson Willms, Ph.D.
Associée de Faculté, Centre d'Etude sur les Etablissements Humains
Professeur Adjointe, École de Travail Social

Encl.

Appendix B: Text of Interview Schedule

UBC Centre for Human Settlements
Project: *Housing for Persons with AIDS in Canada*

Interview Guide

1. For Organizations

For INDIVIDUALS, not representation an organization, start on page 7.
For HOUSING PROJECTS, start here with questions about the organization responsible for it.

1.1 TYPE of organization (Community based, voluntary, quasi-governmental, profit, gov.)
1.2 TARGET GROUP
1.3 HISTORY / background (impetus, starting date, evolution)
1.4 STAFFING (professional, para-professional, volunteer, trained volunteers, co-op, mix)
1.5 FUNDING (gov., foundation, endowments, fees, rents, contracts, membership)
1.6 SERVICES, PROGRAMS, POLICIES
1.7 ORGANIZATIONAL ISSUES, problems

If Case Study Organization, continue. If not go to Housing Project or Service.
If neither, go to housing issues and options.

1A. For CASE STUDY Organizations

1.8 more information about each program/service
1.9 affiliation with other service providers
1.10 management/board of directors
1.11 annual operating budget
1.12 future plans

Go to housing issues and options.

2. For HOUSING Projects, Services, Facilities

2.1 sponsor
2.2 type of accommodation (independent housing, care facility, hospice)
2.3 target group
2.4 objectives, philosophy, approach
2.5 location
2.6 opening date
2.7 number of units/beds and type (1-bed, bachelor, bedsitting room etc.)

2.8 disabled accessible
2.9 number of residents by age, sex, and health status
2.10 impetus for project/service -- background
2.11 tenant selection criteria and referrals by
2.12 vacancy rate
2.13 facilities and amenities
2.14 services/care/support available (include relationships with external agencies)
2.15 innovative features
2.16 total capital costs
2.17 funding sources (municipal, provincial, federal, private)
2.18 rental rates
2.19 number of units subsidized
2.20 managed by
2.21 issues/problems/concerns

If Case Study Housing Project, continue. OR Go to housing issues and options.

2A. For CASE STUDY Housing Projects, Services, Facilities

2.22 when did planning begin? duration
2.23 participation in planning and design
2.24 difficulties/hurdles in planning and design
2.25 plans available (site plan, floor plans, sketches)
2.26 unique design features
2.27 annual operating costs
2.28 operating funding source(s)
2.29 house policies (rents and rent increases, visitors, pets)
2.30 who develops policies
2.31 licensing
2.32 staff (salaried, volunteer)

Go to housing issues and options.

3. For INDIVIDUALS with AIDS, HIV+

3.1 date of diagnosis with HIV/AIDS
3.2 current health status (use 100 cm line for analysis)
3.3 age, sex
3.4 employment or employment history
3.5 previous/current source of income
3.6 support network (family, friends, intimates)
3.7 proximity to services
3.8 service utilization
3.9 housing/support history (begin prior to AIDS diagnosis/HIV test positive and for all subsequent housing changes until the present): where (city, town); type of

housing (SFD, rental apt, shared accommodation); own/rent; housing payments as percent of gross income; problems/issues; why move?

3.10 future housing needs, plans

Go to housing issues and options.

4. Housing ISSUES & OPTIONS

4.1 In general -- *i.e., separate from the PWA/HIV housing issues* -- what are the major housing issues in this city?

4.2 Is housing for persons with AIDS and HIV infection an issue in your community?

4.3 In what way is it an issue? Describe as fully as possible.

4.4 What is your estimate of the number of people with housing needs among the HIV/AIDS community?

4.5 What is the relative seriousness of the various aspects of the housing problem in your view?

4.6 Can you estimate the relative size of housing need according to:
health status or degree of disease progression?
type of housing/care needed?
by target group?

Reminder to Interviewers: possible definitions of the range of housing issues.

affordable	cost of housing within financial resources of those in need; e.g., spending max 30% of gross income
available	housing units are available by type and location; sufficient vacancies, secure tenure
accessible	discrimination and neighbourhood resistance: access to the available units in the community
appropriate	suitability of the unit, e.g., for disabled individuals, for support and care services and facilities
adequate	structural condition of the housing units: good physical condition, physically safe and healthy

Housing OPTIONS

4.7 What are the most appropriate approaches or philosophies to housing and care for PWA?

4.8 Describe your "wish list" of housing/care options for PWA & HIV+.
That is, if you were in charge, what would you implement?